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Parental resistance: Mobile and transitory discourses
**A discursive analysis of parental resistance towards medical
treatment for a seriously ill child**

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Martin Woods

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Abstract

This qualitative thesis uses discourse analysis to examine parental resistance towards medical treatment of critically ill children. It is an investigation of the ‘mobile and transitory’ discourses at play in instances of resistance between parents, physicians and nurses within health care institutions, and an examination of the consequences of resistance through providing alternative ways of perceiving and therefore understanding these disagreements.

The philosophical perspectives, methodology and methods used in this thesis are underpinned by selected ideas taken from the works of Michel Foucault and Pierre Bourdieu and supported by relevant literature in the fields of media, law, children, parenting, caring, serious childhood illness, medicine and nursing. The thesis obtains information from a variety of texts that includes established literature (such as medical, sociological, legal, academic and philosophical), newspaper articles, radio or television interviews, internet sources, court reports and proceedings, legal experts and other commentators – and 15 interview based texts, where the focus is on analyses of narratives of parents, doctors and nurses.

In the texts gathered for this thesis, there are noticeable differences between the personal experience discourses of parents, the ‘in-between’ discourses of nurses, and the disciplined discourses of physicians. This thesis brings these discourses into conversation with each other suggesting that parental resistance does not occur because of an infrequent and unusual set of circumstances where a few socially isolated and/or ‘difficult’ parents disagree with the treatment desires of paediatric physicians. Instead, it is argued that from an examination of interview based texts, parental resistance is an omnipresent but transitory occurrence that affects many of the interactions between the parents of seriously ill children and clinical staff. It is maintained that within these interactions, the seeds of this resistance are sown in both critical decision making situations *and* in everyday occurrences between doctors, nurses and parents within healthcare institutions. Contributing factors to parental resistance include the use of power games by staff, the language of medicine, forms of symbolic violence, the presence or absence of trust between parents and medical staff, the effects of medical habitus, and challenges to the parental role and identity.

Overall, it is proposed in this thesis that parents who resist treatment for their seriously ill child are not exceptions to the normative patient-physician relationship. Instead an analysis of their discourses and practices is able to illuminate the complex interactions between patients and medical conventions. It is therefore possible to see parents who resist medical advice not as peripheral to the medical encounter but as examples of how patient-physician relationships come to be codified, constructed and crafted through everyday discourses and practices within health care settings.

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I have lived with this research project for a considerable number of years of my life; and (to misquote W.H. Auden) it has been my morning, my noon and my midnight for a good deal of that time. Yet, as I now reflect on those years, I am mindful of those who supported me in its production.

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Dedication

This thesis is dedicated to the memory of
David Woods
(*b.* 11 February 1947; *d.* 23 February 1947)

"Oh, little body, do not die.
You hold the soul that talks to me
Although our conversation be
As wordless as the windy sky"
(Excerpt from *A Child Ill* by
John Betjeman, 1964/2006).

Table of Contents

LIST OF FIGURES	XI
CHAPTER ONE - PARENTAL RESISTANCE: INTRODUCTION AND OVERVIEW ..	1
INTRODUCTION.....	1
AIM.....	2
The overall philosophical approach to the study.....	2
Use of terminology.....	3
Examples of parental resistance	4
Examples of ‘radical’ parental resistance.....	6
INTERNATIONAL EXAMPLES OF PARENTAL RESISTANCE	10
United States of America	11
Australia	12
Canada.....	13
The United Kingdom.....	13
AN OVERVIEW OF THE STUDY	15
ORGANISATION OF THE THESIS	16
CHAPTER TWO - PHILOSOPHICAL PERSPECTIVES, METHODOLOGY AND	
METHODS	20
INTRODUCTION.....	20
POSTMODERNISM AND POSTSTRUCTURALISM	20
Poststructuralist inquiry in social and health related research.....	22
FRENCH POSTSTRUCTURALISM IN SOCIAL THEORY – BOURDIEU AND FOUCAULT.....	23
Foucault – the main ideas used in this thesis.....	25
Bourdieu – the main ideas used in this thesis.....	34
The theoretical connections between Bourdieu and Foucault.....	40
RESEARCHING PARENTAL RESISTANCE.....	41
Method	41
Design	42
THE USES OF PUBLIC TEXTS.....	43
The media.....	43
The judiciary	44
Established literature	44

Self involvement in the literature	44
THE USE OF INTERVIEW BASED TEXTS	45
Ethical committee approval and use of information.....	45
Procedures for recruiting participants and obtaining informed consent.....	46
Finding participants	47
Contextual and procedural elements	48
Transcription	49
ETHICAL CONCERNS	49
Privacy Issues	50
Informed Consent.....	50
Confidentiality and use of results	50
Anonymity and other issues	51
Potential Harm to Participants.....	51
Other risks	52
ANALYSIS OF TEXTS.....	52
Consistency and credibility issues.....	54
SUMMARY	55
CHAPTER THREE- CONSENT, DECISION MAKING, THE LAW AND PARENTAL RESISTANCE	56
INTRODUCTION.....	56
CHOICE AND CONSENT IN HEALTH CARE	57
New Zealand legislation – informed consent	58
THE CONCEPT OF INFORMED CONSENT IN MEDICAL PRACTICE AND LAW.....	59
The professional practice standard	60
The reasonable person standard	60
The subjective standard.....	61
THE LEGAL CONCEPT OF INFORMED CONSENT IN REGARD TO CHILDREN AND THEIR PARENTS	62
The Crimes Act 1961	64
Children, Young Persons and their Families Act 1989	65
The Care of Children Act 2004	65
PARENTAL REFUSAL OF CONSENT IN HEALTH CARE SETTINGS	67
Representations of the causes of parental resistance in literature	68
On religious grounds.....	68
A preference for less invasive treatment	69

Distrust of the health care system/physicians/drug companies	70
Different socio-cultural beliefs and values	70
Psychological factors.....	71
Ignorance, neglect, and/or malice.....	72
DECISION MAKING IN HEALTH CARE SETTINGS.....	73
The concept of an individual's 'capacity to choose' in law	75
Representations of medical decision making	76
The concept of 'best interests'	77
Medical decision-making models.....	79
The paternalistic model	79
The partnership model.....	80
The participation - involvement model	81
The shared decision making model.....	82
Representations of parental decision making	83
The concept of parental autonomy	84
SUMMARY	86

CHAPTER FOUR - MEDIA REPRESENTATIONS OF PARENTAL RESISTANCE.... 88

INTRODUCTION.....	88
THE ROLE OF MEDIA IN CASES OF PARENTAL RESISTANCE	90
The power of the media.....	91
The methods of the media	93
Media 'framing' of cases of parental resistance.....	94
MEDIA REPRESENTATIONS OF PARENTAL RESISTANCE.....	97
Parents as 'culturally different'	98
Parents as misguided and/or misinformed individuals.....	100
Parents as ignorant and/or malicious.....	102
Doctors as proper representatives of medical treatment.....	106
Alternative therapists as 'quacks'	107
Suffering children as innocent heroes ...but resisting parents as unheroic.....	109
Suffering children and their (conforming) parents as heroic figures.....	110
The law as the state sanctioned arbiter of societal behaviour	111
The media as critics and conscience of society	114
SUMMARY	115

CHAPTER FIVE - LAW, MEDICINE AND PARENTAL RESISTANCE.....	117
INTRODUCTION.....	117
THE ROLE OF THE LAW IN CASES OF PARENTAL RESISTANCE	119
Legal theory and legal process	119
Legal discourse.....	121
The use of legal regulation to modify (parental) behaviour	123
Legal narratives	125
THE LEGAL RESPONSE TO PARENTAL RESISTANCE	126
Constructing parental identity and behaviours - state legislation & jurisdiction.....	126
Categorising parents through law.....	130
Regulating parental resistance to medical advice through law.....	131
The law as the delimiting arbiter of ‘ordinary v strange’ parental behaviour	136
Maintaining the role as the arbiter of parental behaviours.....	138
SUMMARY	141
CHAPTER SIX - THE ANTAGONISM OF STRATEGIES: EXPLORING PARENTS’	
TALK ABOUT THE PARENT-PHYSICIAN RELATIONSHIP	143
PARENTS’ STORIES	144
Mary’s story	145
ANALYSING PARENTS’ STORIES	152
The impact of the medical ‘field’	154
Power games – parental relationships with the medical team.....	155
The language and rules of medicine.....	158
Trust-mistrust between parents and medical staff.....	161
The effects of medical habitus.....	164
Facing the challenges to the parental role	166
The challenge to parental identity	168
THE DEVELOPMENT OF PARENTAL RESISTANCE	170
The predisposing elements of parental resistance	170
THE EMERGENCE OF PARENTAL RESISTANCE – THE ANTAGONISM OF STRATEGIES.....	175
Using the system and playing the part.....	176
Standing ground	179
Taking back control.....	180
Maintaining control.....	181
SUMMARY	182

CHAPTER SEVEN - COMMUNICATION, NEGOTIATION AND COMPROMISE:

EXPLORING PHYSICIANS' TALK ABOUT PARENTAL RESISTANCE 184

INTRODUCTION.....	184
DOCTORS' VIEWS ON PARENTAL RESISTANCE	185
DISCURSIVE THEMES IN PHYSICIANS' RESPONSES TO PARENTAL RESISTANCE.....	195
Medical field, habitus, and social capital	195
The physician-parent relationship	198
DOCTORS' RESPONSES TO PARENTAL RESISTANCE	199
Maintain the relationship.....	201
Improve communication	202
Change the language	203
Negotiate	204
Attempt compromise	205
Revert to paternalism	207
Reattempt all previous negotiations/compromises.....	207
Permit harmless alternative treatments/therapies.....	209
Redefine the meaning of 'normal' treatments.....	210
Seek support within the institution.....	212
Use the law as an ally	214
SUMMARY	216

CHAPTER EIGHT - BEING 'IN-BETWEEN': EXPLORING NURSES' TALK ABOUT

PARENTAL RESISTANCE 217

INTRODUCTION.....	217
NURSES' VIEWS ON PARENTAL RESISTANCE	218
DISCURSIVE THEMES IN NURSES' RESPONSES TO PARENTAL RESISTANCE	221
The nursing field and habitus	221
Nursing as 'in-between' in parent-physician disputes.....	223
Nursing as 'caught between' resistive parents and physicians.....	226
Nursing operating between old and new professionalism in parent-physician disputes ...	230
NURSES' RESPONSES TO PARENTAL RESISTANCE.....	234
The nurse as a medical collaborator	234
The nurse as a 'team player'	236
The nurse as the patient's/parents' advocate	239
The nurse as an expert 'go-between'	241

SUMMARY	242
CHAPTER NINE: PARENTAL RESISTANCE REVISITED: ‘MOBILE AND TRANSITORY POINTS OF RESISTANCE’	243
INTRODUCTION.....	243
PARENTAL RESISTANCE – A COMPLEX ISSUE	243
PARENTAL RESISTANCE – CONVERGING AND COMPETING DISCOURSES	248
STRATEGIES FOR CLINICAL STAFF IN RESPONDING TO PARENTAL RESISTANCE	250
IMPLICATIONS FOR EDUCATION AND PRACTICE.....	252
LIMITATIONS OF THE STUDY	254
SUGGESTIONS FOR FUTURE RESEARCH	255
CONCLUSION	256
REFERENCES.....	257
APPENDIX 1: LETTER OF INTRODUCTION	287
APPENDIX 2: INFORMATION SHEET	288
APPENDIX 3: INFORMATION SHEET	290
APPENDIX 4: CONSENT FORM	292
APPENDIX 5: CONFIDENTIALITY AGREEMENT	293
APPENDIX 6: SELECTION OF NATIONAL MEDIA/NEWSPAPER/RADIO REFERENCES.....	294
APPENDIX 7: INFORMATION FROM THE MINISTERIAL ADVISORY COMMITTEE ON COMPLEMENTARY AND ALTERNATIVE HEALTH.....	297

List of Figures

FIGURE 1:	A SELECTION OF NEWSPAPER/WEB-BASED HEADLINES CONCERNING PARENTAL RESISTANCE, 1999 – 2005.....	96
FIGURE 2:	AN EDITED TRANSCRIPT FROM THE TELEVISION PRESENTATION ‘THE TRIBBLE CASE’.....	97
FIGURE 3:	MEANINGS IMPLIED BY LANGUAGE USE IN THE NEW ZEALAND HERALD.	112
FIGURE 4:	LEGAL RECORD KEEPING: R V LAUFAU.....	124
FIGURE 5:	JUDGE POTTER, SENTENCING REMARKS, REGINA V P. & F. LAUFAU.	126
FIGURE 6:	DISCURSIVE POSITIONING OF THE MEDICAL PROFESSIONS.	135
FIGURE 7:	PARENTAL ACTIONS THAT ARE POSITIVELY OR NEGATIVELY SANCTIONED BY PHYSICIANS.....	201
FIGURE 8:	OLD PROFESSIONALISM-NEW PROFESSIONALISM.....	232

CHAPTER ONE

Parental resistance: Introduction and overview

Where there is power, there is resistance, and yet, or rather consequently, this resistance is never in a position of exteriority in relation to power (Foucault, 1979, p. 95).

Introduction

This thesis owes its existence to a number of coincidences and interconnected developments that first caught my attention seven years ago and have remained in the forefront of my thinking ever since. In 1999, a headline caught my eye as I read a national newspaper. It read: “Parents dice with boy’s life” (Cleave, 1999) and it featured a short article about parents who had gone into hiding within New Zealand to avoid further medical treatment for one of their children. The child was diagnosed as having a facial neuroblastoma¹ but the parents did not wish their child to be treated with anti-cancer drugs. At the time, it seemed a terrible thing to me that the parents should feel so strongly about their child’s proposed medical treatment that they found it necessary to go into hiding to avoid the medical profession and the law. Why, I mused, would seemingly ordinary parents take such drastic action? Were there any other incidents like this one in New Zealand? Was this phenomenon an international trend, and if so, what were the causes and possible ramifications for parents, the medical professions, and for society itself of such a trend?

For years, as a nurse and a nurse educator with a particular interest in ethics and law, I had been aware of the dilemma faced by parents who were Jehovah’s Witnesses when it was deemed necessary to give their child a blood transfusion. The medical response to such a situation was almost routinised, i.e. the child was ill, seen by doctors, a blood transfusion needed, the parents refused, the child was made a ward of court, the blood given, the parents and child eventually went home. I had taken it for granted that such a situation was a minor anomaly in what was otherwise a relatively trouble free and orderly system. But this was not necessarily so. After the original case (Cleave, 1999) caught my eye, I collected other cases over the years, both nationally (Johnston, 2000; Clarke, 2001; Carter, Stickley, Inglis, & Laxon, 2002; Osborne, 2003; Trevett, 2003) and internationally (Carrick, 2002; Mallia, 2002; Jarvik & Dobner, 2003; Diekema, 2004; Jackson, 2004; Gronli, 2005) of parental resistance to proposed medical treatment of a seriously ill child.

¹ A highly malignant tumour that is fatal if untreated.

As I reviewed those cases, I came to recognise the common features of ordinary parental resistance, and especially those cases that exhibited features that went beyond resistance into the realms of the 'radical.' Although the five high profile cases selected for study were of a radical nature and four of them were highly publicised in the media, there were also other instances of parental resistance that were only reported in legal publications and not the popular media such as newspapers or radio.² It became clear to me that the boundaries between radical and non-radical parental resistance were quite fluid. In fact, there appeared to be 'an explosion of discourses' (Foucault, 1977) in the media around parental resistance from a range of different perspectives.³ Furthermore, these discourses were increasing over time and certainly not abating. Each new case was overlaid on an established set of understandings about parental resistance to medical treatment, shaping the way that the media, health professionals and the general public viewed the 'facts' as they were released. This thesis is about incidents of resistance amongst both the users and providers of health care.

Aim

The aim of this study was to investigate the discursive elements at play in instances of resistance between parents and physicians regarding the proposed medical treatment of critically ill children.

The objectives were:

- a) To perform a comprehensive examination of the major discursive themes and fields involved in situations of parental resistance where both parents and physicians are faced with difficult decisions concerning the medical treatment of a child.
- b) To supply an analysis of the various discourses associated with parental resistance to medical treatment with the overall objective being that of providing alternative ways of perceiving and therefore understanding the discursive elements at play within.

The overall philosophical approach to the study

Originally, I had intended to use analytical methodology based on philosophical enquiry. However, after a period of reflection and further consideration, it became clear that the philosophical enquiry method would not do justice to the range of media, legal and medical texts that were emerging concerning the topic. Furthermore, it occurred to me that the stories and narratives of the parents needed to be included so that an analysis of events from the

² Such as *Auckland Healthcare Services v Liu* (1996 HC Auckland, M812/96).

³ See media commentaries (Ansley, 1999; Chisholm, 2000; Masters, 2002; Witchel, 2002); official opinions from national figures (McClay, Commissioner for Children, cited by Grunwell & Alexander, 1999; Stent, Health & Disability Commissioner, cited by Keane & Newth, 1999), medical opinion (Paediatric Society of New Zealand & Board of Paediatric & Child Health of the Royal Australasian College of Physicians, 2001), bioethical and medico-legal opinions (Carrick, 2002), religious opinion (Osborne, 2003).

parents' perspectives would not be absent. As a result the analytical agendas within the thesis go beyond the socially descriptive and philosophically analytical, toward an enquiry that is a critically reflective and creative study of people and their life worlds.

The analytical grounding of the thesis draws on the main works of Foucault (1970, 1972, 1973, 1975, 1977, 1979, 1984b-e) and Bourdieu (1977a, 1984, 1988, 1990a, 1990b, 1990d, 1991, 1992). Foucault's ideas about power, knowledge, discipline, governmentality, and resistance were significant to an analysis of radical resistance in an area of health care. In particular, the thesis draws on Foucault's method of *deconstructing* texts in order to explore how various discourses may be perceived, analysed and represented. Bourdieu's ideas about capital, habitus and field⁴ were also relevant to the thesis agendas because they helped to 'ground' the thesis within the health care setting. The concept of *capital* is used to analyse relations between actors in the field. The concept of *habitus* underpins ideas about 'structuring structures' within health care settings where parents, their children and the medical professions confront each other. Bourdieu's work provides a sense of orderliness within a sometimes very disorderly collection of conflicting texts, and, curiously, a radical way of *reconstructing* the texts that enabled a sense of balance to be achieved.

Hence, for all of the above reasons, discourse analysis was selected as an appropriate method for this study. Such an approach enabled the development of an epistemological position that explored complexity, celebrated diversity and enabled multiple readings of the topic.

Use of terminology

For the purposes of this thesis, the following working definitions of both 'parental resistance' and 'radical parental resistance' were developed:

Parental resistance indicates those situations when a parent or parents do not readily accept the advice of physicians concerning the proposed medical treatment of their child.

Radical parental resistance indicates fundamental opposition to medical wishes by parents, which leads to radical actions and consequences involving resistance to medical treatment and/or resistance to the legal process (such as running away, going into hiding, ignoring medical pleas to intervene).

⁴ Habitus is defined as a system of durably acquired schemes of perception, thought and action, engendered by objective conditions but tending to persist even after an alteration of those conditions. It is the product of social conditioning and so links actual behaviour to class structure. Fields refers to different sets of social "rules" that apply in different contexts. To gain entry to a field or to participate in activities within a field, different forms of resources are drawn upon, or contributed. Such resources are characterized as various forms of capital (see Chapter Two).

These definitions of parental resistance are based upon Foucault's (1980a) ideas on power and resistance as opposition to an idea or an act that manifests itself as either a spontaneous or considered response that may present in a number of ways ranging from passive or submissive to active or assertive. Examples of parental resistance and radical parental resistance in the national and international contexts are set out in the following sections.

Examples of parental resistance

As previously indicated, the majority of reported legal cases of parental resistance to proposed medical interventions over the past decade have involved the ordering of blood transfusions for Jehovah's Witness children against their parents or family's wishes (as in, for example, [1995] 2 NZLR 73; *Re J* [1996] 2 NZLR 134). In the latter example, the child J, was admitted to hospital because of a severe nose bleed. After J's parents refused a blood transfusion, the District Court judge authorised it under The Children, Young Persons and their Family Act, 1989 (CYPFA). Later, it was shown that the High Court (rather than the District Court) held inherent jurisdiction as *parens patriae* to give consent under the Guardianship Act (1968). It was held that case law showed that the Court would always intervene despite parents' beliefs where a child's life or well-being was seriously threatened and that the child's right to life (under section 8 of the New Zealand Bill of Rights Act, 1990) overrode parents' right to freedom of religion and belief and otherwise general power to decide upon child's medical treatment (*Re J* [1996] 2 NZLR 134). This judgement is typical in cases involving children belonging not only to the Jehovah's Witness, but Christian Scientist and sometimes Pentecostal faiths as well. Essentially, in all cases where 'strong religious views' are found to prevent parents from giving their permission for medical interventions, the courts take the now well established view that "the parent's right to practise their religion could not extend to risking the life, health and welfare of a child" (Court of Appeal decision, [1995] HC Napier, CP17/95, CP19/95).

However, not *all* cases of parental resistance involve children and parents of a particular religious faith; some cases represent other significant differences between parents and physicians. For instance, in 1996, there was a case involving the refusal of a parent to allow her child to have medical treatment to reduce the risk of blindness (*Auckland Healthcare Services v Liu* ([1996] HC Auckland, M812/96). This example illustrates a court ruling in a case which involved serious consequences for the child. Another case involved a Samoan family who refused surgery for their young child who suffered from Ewing's sarcoma. In this instance, the parents were taken to court and the child was placed under the care of the hospital doctors for treatment (*Re Norma* [1992] NZFLR 445). In another case, a two-year-old child was placed

under a guardianship order to enable surgeons to surgically treat suspected testicular cancer (HC [Auck] M 708/97) against the wishes of his parents.⁵

The cases noted thus far generally failed to ‘catch the public eye’ because they were often dealt with outside the public gaze, and were either underreported or not reported at all in popular media. In these cases, the parents acquiesced to the wishes of the court, and would not therefore be considered as newsworthy because their responses were routine ones. It is of note, however, that this entire process, i.e. from parental resistance to the law courts, represents a *particular* routine, and most certainly a dominant discourse, where medicine, law and the state appear to concur in nearly all aspects of response. In more recent times other situations involving parents, their children and the medical profession have resulted in court appearances for the parents to face criminal charges. One such case involved the parents of a seriously ill child who were in court in 2001 for failing to provide the necessities of life when their toddler developed meningitis. They did not wish to use antibiotics and instead waited for a sign from God, only later taking their child to hospital. In this case, the child survived and no further actions were taken (Witchel, 2002).

Some cases may be seen as underrepresented in the media but still involve parents ignoring medical requests to intervene and/or running away with their child. These cases exhibit some elements of ‘radical’ resistance and are therefore identified in this thesis. For instance, in 2000, a 6 year old child died in the Starship hospital five months after his parents refused life-saving radiotherapy and ‘fled the country’ back to the Cook Islands with him (Johnston, 2000). Previously, surgeons had removed a brain tumour but his parents objected to the follow-up radiotherapy on religious grounds and because their son feared he would die if put back into the CT scanner machine. Doctors gave the boy a 65 to 75 per cent chance of survival after his surgery if he underwent a six-week course of radiotherapy, but said that without it he would die. Nevertheless, the child’s parents took him home to Rarotonga before Auckland Healthcare’s legal bid for guardianship could be heard. As a consequence, Auckland Healthcare withdrew its guardianship application in the High Court. Back in the Cook Islands, the child did well for a few weeks, but later suffered serious pain and brain damage as the tumour grew back. His mother rushed him back to the New Zealand Hospital, but it was too late and he eventually died. The father of the Cook Islands boy, whose name was suppressed, later said that he was worried

⁵ There are a number of similar cases, as in for instance, Re CL [1992] NZFLR 352; Re V [1993] NZFLR 369; Re J [1996] 2 NZLR 134; Re M (Child: Refusal of Medical Treatment) [1999] 2 FCR 577; Re MM (Medical Treatment) [2000] 1 FLR 224.

about legal action if he and his wife returned to Auckland. The father is on record as saying "In my position I would rather have him not go through the treatment. We were expecting for miracles to take place but then it was God's will. The life of every human being is programmed by God" (Johnston, 2000). The Cook Islands Minister of Health commented that many unsuccessful bids were made to persuade the parents to take the boy back to the New Zealand Hospital in time for radiotherapy to help. "In the end their decision killed their child" he said. His Government decided against making the boy a state ward because he was so fragile. Had he died in state custody, he noted, "...the parents and people would never forgive us" (Johnston, 2000).

The 'Cook Islands' case is of considerable interest in that it represents an example of the State 'giving up' when the child and parents leave one country for another. This seems especially possible in those situations where family members share dual citizenship or at least have the ability to travel abroad. A similar case occurred when a British family left the United Kingdom for New Zealand against medical advice when their child required a liver transplant (ReT [1997] 1WRL 242). In this instance, the mother of the child returned to the United Kingdom later to face the legal system, from which she was eventually exonerated. A third and similar case of 'nation hopping' under duress occurred several years ago when a court in the UK ordered that a young child whose mother was HIV positive, be tested for the disease. The parents, who didn't believe in conventional anti-AIDS medical treatments (the father was reported as 'an alternative health practitioner'), fled with their child to Australia and settled there anonymously. The authorities only became aware of the child when her mother, now close to death, was taken to hospital. After the mother died, the authorities intervened and tested the child for the disease and wished to proceed with a suitable (medical) treatment regime. At that point, the father fled with his daughter, but was soon discovered in another state, and a magistrate ordered that they return to the United Kingdom, where the child was made a Ward of the state (Carrick, 2002).

As may be seen in all of the cases noted above, parental resistance appears as both a local *and* an inter-national phenomenon where the contextual arena is of considerable interest because the mechanisms for dealing with resisting parents are similar in those countries that share a comparable system of medicine and law. What follows in the next section is a chronological introduction to a selection of cases from both New Zealand and overseas that exhibit the elements of radical resistance and the media, legal, medical and state forms in which they are embedded.

Examples of 'radical' parental resistance

Over the last few years, a handful of New Zealand cases have stood out from other cases of parental resistance in that they exhibit the elements of radical resistance including initial

parental resistance, the fundamental refusal of the parents to accept medical advice, use of the legal system, media coverage and the eventual fatal consequences for the children involved. These cases are outlined in order of occurrence over the last decade.

Baby L

In 1998, a baby girl (“Baby L”) was born two months prematurely at a national hospital with a severe brain stem disorder that, as time went by, prompted the staff in the Neonatal Intensive Care Unit (NICU) to carefully and extensively discuss the possibility of withholding or withdrawing care for the baby. This was because, in their opinion, of the apparent futility in continuation of medical treatment. When the parents of Baby L were involved in this process, they were at odds with the unit’s team, and sought to have treatment continued. Following a review of the situation by the hospital’s ethics committee, where the primary neonatologist’s view was supported (the ethics committee decided that Baby L’s treatment was “futile and therefore inhumane”) a decision was made to apply to the court under the Guardianship Act, 1968. The doctors took the case to court, where the “best interests” test was applied by considering the relevant rights of the child, the therapeutic benefit of any treatment, the chance of recovery, the impact of the treatment on the child and the parents’ views (*Auckland Healthcare Services Ltd v L* [1998] 17 FRNZ 376). Later, it was found that all of the above factors favoured the hospital’s application but not the parents’ views. The doctor in charge of Baby L was made her legal guardian and the decision was made by the Neonatal Care Unit staff to withdraw treatment. This occurred later when the baby was returned home and removed from her ventilator. Baby L died at home surrounded by her family, friends and some of the nurses who had cared for her. The case is of interest because it was largely unreported in the media at the time, but has achieved a level of notoriety by setting a legal precedence, and being frequently quoted in a variety of other legal (e.g. Harder, 2002), medical/bioethics (e.g. Manning, 2001) and nursing ethics (Woods, 2001) texts.⁶ Essentially, it is a case of parental resistance to medical advice to *discontinue* treatment that led to legal actions that were instigated by the medical authorities. In this way it may be argued that, the particular circumstances aside, the whole apparatus of the state swung into place behind the medical profession.

⁶ It is probable that this case, and perhaps other previous cases involving the rationing of medical resources (such as the ‘Rau Williams’ case [Venter, 1997]), sensitised the media, and thereby the public, to possible cases involving resistance (of the parental or medical kind) or to issues surrounding the use of medical resources in debatably futile medical treatments in the future.

Liam Williams-Holloway

In 1999, a case ‘hit the headlines’ and was very widely publicised for several months (Ansley, 1999; Cleave, 1999; Collie, 1999; Dearnaley, 1999, 1999a; Perry, 1999). It involved a 4-year-old child (Liam Williams-Holloway) who was diagnosed with a rare form of neuroblastoma. After seeing the child, a Paediatric Oncologist prescribed a course of intensive chemotherapy, arguing that this was in the child’s best interests and gave him the best chance to live against the odds. After one course of treatment, the child’s parents decided to withdraw their son from the prescribed treatment programme, and seek alternative treatment, which included the use of an electrical device, called a “quantum booster.” The doctors insisted that their son be treated by means of chemotherapy, and to ensure this, the doctors applied for, and were granted, a court guardianship order over the child (Healthcare Otago Ltd v Williams-Holloway [1999] NZFLR 804 & 812). However, the family went into hiding for four months until the guardianship order was lifted. During this time, and for some months later, public and media interest was intense, with a high degree of public sympathy for the parents in evidence (Stent, cited by Keane & Newth, 1999; Chisholm, 2000). Later, after receiving both a short course of traditional and a longer course of alternative treatment at German and Mexican clinics, the child died. This case, and the increasing likelihood of encountering others with similar features in the future, caused members of the medical profession in New Zealand to re-examine their overall approach to difficult ethical cases involving seriously ill children (Chisholm, 2000; Paediatric Society of New Zealand and the Board of Paediatrics and Child Health of the Royal Australasian College of Physicians, 2001); and the media to reflect on the possible repercussions of the case (“Liam’s parents not alone in cruel cancer dilemma”, 1999). Because this case represents an archetypal case of parental resistance (towards both the medical and legal ‘authorities’) it serves as one of the major ‘texts’ within the study.

Tovia Laufau

In 1999, another case, often now referred to in conjunction with Liam’s case by reporters and others, became national news. A 13-year-old boy, Tovia Laufau died at home in Mangare, Auckland from the effects of an untreated tumour on his knee (Taylor & Chisholm, 1999). The child would not return to hospital for treatment after an initial visit and subsequently his parents declined medical intervention because they believed that God would save the child. As a result, Tovia was nursed at home until his death, and it was only afterwards that the medical authorities combined with the legal authorities to bring his parents to trial.

The parents later argued in court that their primary reason for not presenting their son for treatment was related to the ‘clear and informed choice’ that their teenage son had made for himself (R v Laufau, 2000). Nevertheless, in this instance, the court ruled that the parents should have insisted on treatment and they were later convicted of manslaughter and failure to

provide the necessities of life received a suspended sentence of 15 months. It is important to note that it has been maintained that a court order was not sought in this case because of the negative publicity surrounding the Liam Williams-Holloway case at that time (McClay, 1999, cited by McLoughlin, 2000; Taylor & Chisholm, 2000). This case clearly illustrates issues relating to a young person's autonomy, parental control and medical hesitancy; it also represents those situations when the 'routinised' processes or responses of the authorities break down. That is, the medical profession 'stood aside' in this case, and when the legal apparatus was finally brought into play, the child had already died.

Caleb Moorhead

In the Moorhead case, which emerged in 2001-2002, an infant died because of parental failure to provide the necessities of life, and the parents were jailed for 5 years each (Carter et al., 2002; R v Moorhead). This case gained a huge amount of public interest not least because the parents were seen as being largely intransigent in the face of imminent disaster. Their six-month-old infant, Caleb, died from broncho-pneumonia associated with anaemia and brain damage caused by a deficiency of vitamin B₁₂.⁷ His breast feeding mother is thought to have been the cause of his deficiency because she was a strict vegan and was therefore not supplying herself with a diet that assured a supply of healthy breast milk. His death was considered at the time to have been preventable because all medical attempts to save his life had been confounded by the actions of his parents. The attending paediatrician was so concerned about his condition and 'the lack of understanding shown by his parents', that he contacted the Children's, Young Persons and their Families Service (CYPFS) the next day to arrange a court order to remove Caleb from them if it became necessary. The parents fled into hiding with their child because they believed their son could be treated with prayer, and 'home remedies' that included poultices, cayenne pepper and garlic. Some days later a friend of the family and a social worker for CYPFS persuaded the family to return to the hospital. At the meeting, the paediatrician told the parents their son would need a MRI scan. Eager not to lose their co-operation, the paediatrician talked through some 'possible compromises' and they agreed to call him back that night. This, they did not do; the paediatrician lost contact with them, and the police became involved. They were in the planning stages of a house-to-house search by late March, but it was too late. In the early hours of the morning, Caleb's parents woke to hear him breathing heavily as if he was having an asthma attack. They tried one of their usual alternative remedies, i.e.

⁷ A blood test during pregnancy had confirmed Deborah Moorhead had low B12 levels, and Caleb was running out of the essential vitamin because of insufficient B12 in his mother's breast milk.

cayenne pepper up his nostrils to stimulate breathing, but an hour later he died. This case exhibits all the features of radical parental resistance; it contains parental resistance from the outset, medical unease, the literal flight of the parents from the hospital, their going into hiding to escape the law, the death of the child, a court case and a high degree of media interest that culminated with public condemnation of the parents (as in, for instance, Witchel's [2002] blistering verbal attack in the media after the trial).

Caleb Tribble

Finally, a case involving the death of a four month old infant called Caleb who died of complications of a kidney infection (septicaemia) that was not diagnosed and treated medically because the parents wanted to use prayer to heal their child (Osborne, 2003; Trevett, 2003). Following some days of poor health, the infant had been seen by a district nurse who recommended that he be taken to a doctor, but his parents had declined to do so. They maintained that the child had started to improve dramatically after prayers were said for him (the child's father claimed that the family had strong 'Baptist beliefs' and believed in the healing power of God) and that they thought that he was healed. The nurse urged the parents to take the child to hospital, and they planned to do so the next day. The nurse saw the child the next day, and recorded him to be 'quite happy', but the child was dead within the hour after she had left (Osborne, 2005). When the case got to Court in the form of a depositions hearing, the parents were charged with neglect of their legal duty to provide the 'necessaries of life' (IRN, 2004; Television New Zealand, 2005). Later, they were charged with manslaughter, and at the end of the trial, the parents were found 'not guilty' of manslaughter, but 'guilty' of failing to provide Caleb with the necessities of life, then discharged. This last case therefore represents a type of radical parental resistance, but there is an element of parent compliance in that the parents abandoned their initial resistance and finally agreed to make use of offers of medical assistance. However, their child died before medical help could be of any benefit. Once more, there was considerable media interest in this case, and considerable suffering for the parents and their families.

On further investigation, it became obvious that similar cases had, or were occurring throughout the world, at least in those countries that share a comparable system of medicine and law. Examples of these cases were compiled from the beginning of the research to its end.

International examples of parental resistance

There are examples of parental resistance all over the western world, some more radical than others. A brief outline of relevant cases from four English speaking nations with health care delivery systems that are reasonably comparable with New Zealand's follows to further illustrate the phenomenon of parental resistance, and to show that there is an international trend that links such cases together.

United States of America

In 2001-2002, in a case with similarities to that of the Moorhead case, the 16 month old daughter of an American couple, the Swintons, was taken into medical care (and later into foster care) because she was suffering from severe malnutrition as a result of being denied breast milk, formula and medical care. According to medical authorities:

Sixteen-month-old Ice Swinton weighed only 10 pounds, looked like a 2-or 3-month-old and was half the normal weight of a child her age when authorities discovered her close to death last November. EMS workers rushed Ice from her Queens home to Long Island Jewish Hospital, where doctors diagnosed her with developmental problems, a distended abdomen, fractured bones, a vitamin deficiency called rickets and a lung disorder — all caused by malnutrition, authorities said (Graham, 2002).

Her parents believed in a vegan diet only, and the child was reared on nut milk, vegetables, fruits and oils, which were insufficient for her normal growth and development.⁸ Even when doctors told the couple their baby was on the brink of death, both insisted "there was nothing wrong" and were resistant to (medical) treatment. After a four-month hospital stay, the New York City Administration for Children's Services placed the child in a foster home. Both parents were charged with 'reckless endangerment and endangering the welfare of a child' and faced up to seven years in prison if convicted.

Another case, in the state of Utah, USA, involved Parker Jensen, a previously healthy 12 year old, who was diagnosed with Ewing's sarcoma in April, 2003 following previous investigations of a small growth in the roof of his mouth (Jarvik & Dobner, 2003). His parents refused to accept the attending physician's recommendation for chemotherapy because they feared that the conventional treatment would stunt their son's growth and leave him sterile. Parker's parents wished to opt instead for alternative treatments that included 'antineoplaston therapy' at a private clinic elsewhere. Following the involvement of the Division of Child and Family Services (DCFS), they fled the state when they were ordered by a court to relinquish custody of their son so that he could receive chemotherapy (see Associated Press, 2003). Later, after being charged with kidnapping and surrendering to the authorities, they were allowed to maintain custody of their son if they accepted new rounds of tests and abided by the recommended treatment regime. However, after the tests, Parker's parents argued that the results showed no sign of cancer and sought an independent opinion. Their reticence to proceed with conventional treatment led to the subsequent decision for them to face a medical-neglect

⁸ Recent evidence suggests that young vegans miss out on essential elements such as calcium, selenium, vitamin D, riboflavin and vitamin B12 in their diet (Larsson & Johansson, 2002).

trial in their home state. Throughout the period of controversy, the debate centred on what was called the discovery of 'micrometastatic' cancer cells and the track record of chemotherapy in survival rates for such cancers. Huge media coverage, public meetings and petitions were hallmarks of the case for several months in 2003.⁹

However, there are cases in the USA where the law supports the parents' wishes, and it may be argued that at least in North America, parents' rights seem stronger than elsewhere. For instance, Colin Newmark, from the state of Delaware, was a young boy with Burkett's lymphoma whose parents (who were Christian Scientists) refused to consent to a regimen of chemotherapy that would provide Colin with less than a 40% chance of survival. Delaware's Division of Child Protective Services intervened and wanted to authorize treatment over the objection of the parents. The Delaware Supreme Court rendered the opinion that the parents' decision ought to be respected. In so doing, they distinguished Colin's case from others like those above by pointing to the low likelihood of success (less than 40%) and the high level of risk and burden entailed in the treatment being offered (Diekema, 2004).

Australia

In Australia, five year old Laura Boomsma from New South Wales was diagnosed with a rare Wilms tumour in her right kidney, which was removed about seven weeks later following pre-operative chemotherapy. However, when the physicians then wished to continue with a course of chemotherapy, Laura's parents refused. Consequently, the Royal Children's Hospital in Brisbane made an application to the Supreme Court of Queensland which would have compelled the parents to comply with the treatment of their daughter. Original affidavits presented to the courts on behalf of the hospital are thought to have played down the side-effects of the cancer drugs (Vincristin and Actinomycin-D) being prescribed to Laura. In any event, the case lapsed when the family went to London for alternative treatment (Carter et al., 2002). Laura began this treatment at the Dove Clinic that included high-dosage intravenous Vitamin C combined with 'methods for stimulating white blood cells and destroying cancer cells' ("Parents win right to stop child's chemo", 2002).

In another controversial Australian case, the parents of a child, Eliana Diskin, an infant who died after being fed exclusively on a diet of rice milk, were charged with manslaughter, but at the committal hearing, those charges were dropped. As it transpired, the child had an extensive

⁹ See, for instance, the long list of articles attached to the web based site entitled "Parental rights: In defense of the family against nanny state encroachments" at 'Patrioticsaints.com' (2003).

rash that was caused by being fed a diet of rice milk (Carrick, 2002). However, the rash baffled the physicians because they did not connect the infant's diet to the malabsorption problem until it was too late.

Canada

In Canada, a 13 year old from Saskatchewan called Tyrell Dueck, died after a tumour (an osteosarcoma) on his knee spread to his lungs, and once again, his case provoked similar dilemmas over conventional versus alternative therapies. His parents *and* Tyrell himself had refused further chemotherapy and a recommended leg amputation (Jackson, 2004), preferring instead to rely on God and alternative treatments. The Saskatchewan Government tried twice to gain control over his medical care through the courts and Tyrell was given two courses of chemotherapy by court order against his wishes ("Cancer boy who refused treatment dies", 1999). While the court decision was pending Tyrell's parents were debarred from visiting him for fear he might be abducted. He was assessed by a psychiatrist and deemed to be of normal intelligence but immature in that he said that he could not conceive of disobeying his father. The court ruled in favour of the doctors but meanwhile the disease had progressed to such a point that the doctors decided the surgery would not arrest the spread. At that point, his chances of survival were said to have fallen from 65 per cent to less than 15. In any event, and even though a judge had ordered Dueck to undergo further treatment, he himself steadfastly refused, arguing prayer and herbal treatments would heal him. The parents were then allowed to take their son to Mexico as they had wanted to all along for alternative therapy. The family attended a clinic in Mexico where he was given a slow intravenous drip of laetrile, an extract of apricot pits - a controversial treatment which conventional cancer specialists have widely discredited. Tyrell took daily vitamins, enzymes, amino acids and extracts of shark cartilage. Mr Dueck used a large part of the family's savings trying to save the boy, but it was all to no avail.

The United Kingdom

Finally, from the United Kingdom, three examples of parental refusal or resistance that have some similarities to the New Zealand and overseas cases noted thus far. The first case (as previously noted on page six) involved the parents of a seriously ill child who rejected a liver transplant for their child against medical advice, preferring instead that the child be permitted to live a shorter life in relative comfort (ReT [1997] 1WRL 242). In this instance, the child's middle-class parents, who were both health professionals and 'articulate' (Skene, cited by Carrick, 2002), persuaded the court that it was not in the child's best interests to have a liver transplant because their baby was young, there was also a high risk that the transplant would fail, and therefore that it would be in the best interests of the child to have a brief life unfettered by medical interference. The parents left England before any final legal decision could be made on the case.

In the second case, a couple appeared in the Old Bailey in September 2001 facing charges of child cruelty. The Armenian couple, the Manuelyans (who were once vegans but were later 'fruitarians') were the parents of a nine month old girl named Areni, who died of the effects of malnutrition after being reared on a 'fruit-based' diet alone. After her birth, the family saw a paediatrician who said the baby was not developing properly, and that her mother's breast milk was nutritionally deficient. Later, other doctors and social workers warned against the diet. However, the couple had shown a 'stubborn refusal', and would not follow medical advice. Later, the family went to live on a vegetarian commune in Spain, where they believed Areni's Vitamin D deficiency would be cured by 'sunshine and fruit'. When the couple sought out a doctor back in England, they were told that the child needed to be taken to hospital immediately. This advice was also ignored, and the couple returned home. Some time later, Areni stopped breathing, was taken to hospital and certified dead. She weighed just eleven and a half pounds, and was suffering from severe pneumonia brought on by malnutrition. In Court, Mrs Manuelyan was described by her defending lawyer as "a mother who cared passionately for her children. Perhaps she cared too much" ("Baby death parents spared jail", 2001). The couple were also described as "loving but misguided"; in placing the parents under a community rehabilitation order for three years, the Judge said that what had happened to the family was punishment enough. In a similar case in New Zealand (the Moorhead case), the parents each received five year prison sentences.

In the third case, which has similarities to the Baby L case, a Maltese couple from the Mediterranean island of Gozo learned that their expected twin fetuses were conjoined and looked for medical help in England under an agreement between the Maltese government and the British National Health Service. On the birth of the twins, the medical facts showed that one of the twins would survive (after a series of operations) if her twin were sacrificed. The twin to be sacrificed (called 'Mary' by the press) was in considerable difficulties. She did not have a viable heart/lung complex, and no viable brain, was living upon the life support provided by her sister. The twins had a common bladder and abnormalities of the gastrointestinal tract. It was not clear what the mental status of the twin expected to survive (called 'Jodie' by the press) would be, however it was certain that she would undergo intensive therapy and a series of operations to correct the anatomical defects. Nevertheless, after considering the options of separation, the parents decided – for religious reasons (both parents were Roman Catholics) - not to allow their daughters to be operated on, and to allow them both to die a natural death (Mallia, 2002). Dissatisfied with this decision, the hospital staff at the Manchester Hospital turned to the British court system, which has been historically more willing to overrule parents' objections than the American system, and on the 25th August 2000, the High Court Judge gave a landmark decision agreeing with the clinicians. Despite the judge's ruling, the Manchester clinicians were delayed by an appeal which failed. The arguments had come down to whether the conjoined twins were in fact only one baby and that Mary was in fact 'an aggressor' on

Jodie. The twins were separated, and as predicted, Mary died during the 20-hour procedure but Jodie rapidly stabilized and lived (Gronli, 2005).¹⁰

An overview of the study

The discourses around parental resistance represent an as yet largely unexplored area of study. Yet each case that emerges is overlaid on an established set of understandings about parental resistance to medical treatment, constantly shaping and reshaping the way that the media, health professionals and the general public view the ‘facts’ as they are released. Such developments yield several possibilities about how the discourses about parental resistance may be understood in a more general sense; for instance, whether or not parental resistance is a growing trend; or that there may be an increasing level of distrust of the medical profession in western society, and/or that this distrust perhaps shows itself most acutely or vividly in cases involving young children.

It is pertinent to note that although this thesis deals largely with the more radical examples of parental resistance, such a project may in fact represent a much more persistent trend in health care and the relationships between health care providers and the recipients of that care. Last year, as a nationwide Meningitis B (MeNZB) vaccination programme got underway in New Zealand, yet another example of parental resistance emerged, this time fuelled by a significant degree of support from a variety of organised and well argued sources (Sanders, 2005). However, unlike the comparatively small numbers of radical examples, greater numbers of parents have resisted the programme on grounds that they think it is not safe, or that they have been misinformed about the side effects of the vaccine, or that they feel ‘bullied’ into giving consent (Sumner, Burstyn & Law, 2005). Government sources continue to claim otherwise (Ministry of Health, 2005). Opposition to the campaign grew steadily since its inception, and a significant number of parents refused permission for their children either to be vaccinated at all, or for the necessary second or third times (Sanders, 2005).

Hence, this thesis does not suggest that parental resistance is confined to a small number of parents in the community. Indeed, it could be argued that the cases presented in this thesis are not necessarily exceptions but examples or ‘windows’ of the more radical aspects of a phenomenon through which the interconnections between health professionals, the media, law, medicine and the state may be examined. Although the cases chosen for this project may appear to be limited to a few ‘extreme’ cases, it is now more likely that they are the ‘tip of the iceberg.’

¹⁰ It is of interest to note that Raanan Gillon (Mallia, 2002) and Jonathan Glover (2006), both eminent experts in the field of medical ethics in the United Kingdom, concluded that in this case that the court’s decision was regrettable and that the parents’ views should have been respected.

In short, a study of the radical examples of parental resistance provides a unique vantage point from which to examine a number of factors associated with the (less radical) aspects of the physician-parent relationship, as well as the socially driven institutional expectations that are associated with these relationships.

Furthermore, this thesis will argue that the discourses of parental resistance are not just a temporary state of affairs, but a gradual movement involving what may well be a challenge, or even a 'domain shift' (Bourdieu, 1984) in the present disciplinary domain of medicine and law as a powerful discursive formation in society. In this regard, it is argued that parental resistance is both 'mobile and transitory' (Foucault cited by McHoul & Grace, 1993) and operating within everyday power dynamics rather than within isolated or uncommon events. This thesis therefore aims to draw out the many discourses that are contained within parental resistance within a modern western society, and to show that such discourses represent a particular type of sometimes radical resistance that challenges the more traditional views concerning physician-parent relationships; whilst at the same time revealing the major fields that such discourses occur (or sometimes collide) within. It will be maintained that it is within these fields that conceptual processes such as habitus and use of social capital are being gradually challenged.

Organisation of the thesis

Chapter Two

This chapter offers an explanation of the philosophical underpinnings and methodology of the study. It traces the development of the philosophical paradigms and methods of inquiry considered during the research from poststructuralism and post-structural inquiry to the use of Foucaultian and Bourdieusian analytical methodology. This chapter also explains the methods chosen for the thesis. It presents an overview of the design of the study, its procedures, and use of various texts including those supplied by participants and subsequent ethical concerns, as well as a detailed explanation of the analytical approach to the research. The chapter concludes with discussion about the credibility of the research.

Chapter Three

This chapter, the first to examine selected texts that relate to the thesis topic, is mainly concerned with established literature regarding the causes of parental resistance, decision making, informed consent, and the relationships between children, their parents and the law. It contains an exploration of the concept of decision making, and especially medical and parental decision making. The connections between medical and legal decision making are highlighted because it is argued that the law operates a significant degree of 'body politic' based conservatism that supports medicine but rarely the resisting parents. Later, terms such as 'in the best interests of the child' and 'informed consent' are explored in regard to a proposed treatment for a seriously ill child, and the legal discourse around resisting parents is explored.

Connections are made to the use of media as a recorder of state machinations, and the law, as the standard setter and enforcer of state control. These connections are taken up in the following chapter.

Chapter Four

The various roles of the media are explored in this chapter through the examination of relevant texts that include newspaper articles, radio or television interviews, and internet sources. This approach highlights the discourses that emerge in the media concerning the wider subject of parental responsibilities, and in particular the role that the media plays in providing clearly identifiable themes and human archetypes that are embedded within a range of discursive fields such as parents as culturally different, misguided or malicious; children as heroic innocents struggling against the disease; doctors as the proper representatives of treatment (and alternative therapists as largely 'quacks'), and the law as the state sanctioned arbiter of societal behaviour. It is maintained that in media presentations of parental resistance, there is a symbolic reflection and maintenance of 'mainstream values' which tends to construct resisting parents as being outside of the law and therefore outside of 'ordinary' society. Connections between the role of media and the law that are touched upon in this chapter become the focus of discussion in the following chapter.

Chapter Five

In this chapter, the law is examined in relation to the ways in which legal discourses are framed around cases of parental resistance to the medical treatment of their children. To achieve this, the chapter centres upon legal texts that provide discourses from judicial sources such as legal experts, judges, lawyers, the police and five specific cases heard in New Zealand courts in the last seven years. It is maintained that the law uses resisting parents as a contra-culture whereby the cleavage between 'normal' and 'abnormal' parental behaviour may be differentiated for both surveillance and control purposes. Three major discursive themes in the legal responses to parents who resist medical treatment for their children are discussed at length. These themes explore parental identity and behaviours, the regulation of parental behaviour through the use of normalising judgements, and the connection between state and medicine, which is extended further in Chapter Seven.

Chapter Six

This chapter focuses on the stories of interviewed parents concerning the parent-clinical staff relationship during the treatment of their seriously ill child. The chapter concentrates on one parent's story, supported by extracts from interview texts from other parents who contributed their stories to this research project. Discursive elements of parental resistance are developed from an analysis of their narratives; these elements include the impact of the medical field and habitus on parents; power differences in parental relationships with the medical team; the impact of the language of medicine and symbolic violence; the effects of trust-mistrust between

parents and medical staff, and challenges to the parental role and identity. A central argument within this chapter is that parental resistance is an ever present possibility in all parent-clinical staff relationships where a seriously ill child's treatment and care becomes the central focus of parents, physicians, and nurses. Subsequently, the chapter also examines the ways in which parents develop resistance towards medical interventions through the recognition of predisposing elements such as a loss of faith, trust and hope and/or through the absence of perceived medical altruism. Parental responses, such as using the system, playing the part, standing ground and taking back and maintaining control are discussed.

Chapter Seven

This chapter examines the relationship between doctors and the parents of seriously ill children. The chapter suggests that doctors perceive the causes of parental resistance as largely the result of different religious or philosophically different belief systems, psychological factors, cultural differences or ignorance, neglect or abuse. This is reflected in the existing literature (see Chapter Three). In the presentation of the interviewed doctors' responses to parental resistance, considerable differences of perspective emerge between the doctors' responses and the parents responses based on their realities (as discussed in Chapter Six). Overall, it is argued in this chapter that doctors understand parental resistance as resulting from a lack of access to information, having inappropriate information, and/or not understanding the information that they are given. It is also maintained that doctors tend to expose parents to 'symbolic strategies' that impose the medical agents' vision of the divisions of the social world within a dominant medical discourse. The connections between medicine and law as delegated agents of the state are once more examined.

Chapter Eight

The relationships between nurses and the parents of seriously ill children are the focus of this chapter. The chapter examines nursing discourses on parental resistance by firstly presenting the 'nurses' views' of the causes of parental resistance where once more similarities with both doctors' views and those of existing literature emerge. The major discourse of nursing 'in-betweenness' is highlighted in this chapter. It is shown that nurses operate between the competing demands of the medical system, the institute, the parents and the needs of their child patients. As such, their allegiances to parents and children are tested because they are both parents' supporters and medical collaborators at the same time. Subsequently, it is argued that nurses work with both resistive parents and physicians in an 'in-between' fashion that involves working as a medical collaborator, a 'team player', a contributing member of the team, the expert 'go-between', and as the patient's/parents' advocate. These roles reflect connections to both medical and parental expectations of nurses, although in relation to the narratives of parents (Chapter Six), the interviewed nurses themselves were not always fully aware of the relevance of their actions. The chapter therefore concludes by recognising that the in-

betweenness of nursing is a potentially useful resource that nurses may utilise to great effect in their dealings with resisting parents.

Chapter Nine

Chapter Nine is the concluding chapter of this thesis where the findings of the study are revisited and reviewed. Following an overview of the main arguments within the thesis, discussion is offered regarding the converging and competing discourses that emerge within those arguments, and attention is given to possible strategies that may be employed in response to the issue of parental resistance. In reviewing the main arguments of the thesis, the complexities of parental resistance are made transparent. The chapter draws together the various discursive roles of the media, the law, parents, medicine and nursing and presents them in a comparative summary. The main argument that emerges from this summary is that parental resistance exists within a range of discourses that may be described as involving an ‘antagonism of strategies’ which are played out at various times and places. Overall, it is argued that parental resistance is an ever present reality in healthcare institutions, and that those cases that become radical are only one aspect of a much wider and considerably more diverse discourse. The chapter concludes with an outline of the implications of the research for health care practices and education, notes any limitations of the study and offers suggestions for future research.

CHAPTER TWO

Philosophical perspectives, methodology and methods

Research without theory is blind, theory without research is empty (Bourdieu & Wacquant, 1992, p.109).

Introduction

This chapter offers an overview of the poststructuralist philosophical underpinnings of this study, the methodological approach and the methods that were employed to carry out the research. The chapter commences with a brief outline of the relevance of post-structuralist thought in studying topics within social and health related fields. Discussion ensues concerning the usefulness of contemporary French poststructuralist social thought in qualitative research, and an outline of the main theoretical ideas of Foucault and Bourdieu, which were selected to act as “instruments of analyses” (Foucault, 1980b, p. 62) within this thesis is provided. Theoretical connections between Foucault and Bourdieu are considered as a means to preview the joint inclusion of key aspects of their works in this thesis. Overall, this chapter follows the advice of Bourdieu and Wacquant (1992) by linking the main philosophical ideas in the chapter to key agendas within the thesis; thereby providing a sociological framework for theoretical discussion.

This chapter also provides an overview of the method and design of the study, primarily by explaining the selection of discourse analysis as the main investigative tool. An explanation of the overall design of the study follows, which includes discussion concerning how a range of textual materials were utilized within the thesis, including those gathered from ‘public’ sources (i.e. media and other published material) and those supplied by interview participants. The chapter also discusses the ethical concerns of the research, and concludes with discussion about the credibility of the study.

Postmodernism and poststructuralism

Postmodernism has been described as “a social movement and philosophy that originated among French literary theorists in the 1960's” (Reed, 1995, p.71), and although post-modern ideas were expressed prior to this time¹¹, the movement is now considered as “a rebellion against the formalities of modernity” (Doll, 1993, p.6). Postmodernism is a rebellion against

¹¹ The first implication of a ‘post-modern’ view was used by the artist John Watkins Chapman in the 1870s to signify a shift from one type of artistic impression, i.e. ‘impressionism’ towards a new and yet to be explored type, then loosely termed ‘post-impressionism’ (Jencks, 1995).

structuralism and the underpinning structuralist thinking that is closely allied with the empiricism/positivism of the modernist paradigm. Within that paradigm, the perceivable world of nature and human activities is structured as sets of binary opposites (such as being/nothingness, black/white, hot/cold) and these opposites are considered to be the basic elements that structure or 'frame' meaning. Structuralism therefore implies that meaning may be induced or deduced through a study of 'difference'. Such differences have led to the categorisation of the observable world, including the world of human relationships and behaviours. For instance, in sociology/anthropology, a line may be traced from Augustus Comte's (1975) observations¹² through to the works of Emile Durkheim and Marcel Mauss (1963), Louis Althusser (1969), Max Weber (1978), and Claude Levi-Strauss (1963, 1963a, 1976).

Structuralist ideology remains influential within the social sciences to the present day, and rests upon the notion that there is a definable and observable *social structure* (rather than chaos, anarchy or no particular reliable social configuration). In this approach, human consciousness has little more than a purely receptive capacity; the conclusion being that human reality is a human construction, i.e. no more than a product of representative activities which are both culturally specific and generally unconscious. This idea of the human as a 'subject' - as opposed to the idea of the individual as a stable indivisible ego still holds a powerful influence in many fields (such as ethnology, psychoanalysis, and semiotics). As such, structuralism remains a movement associated with modernist hyper-rationalism, claiming that meaning is to be associated with "timeless and universal structures forming a stable and self-contained system based on binary oppositions" (Appignanesi & Garratt, 1995, p.70).

While structuralism seeks to explain abstract forces within society, it clearly does not deal with the more difficult abstract concepts, such as human values or morality, in that it fails to adequately provide reliable meaning or motivation of any given ('subject') individual (Bauman, 1992). Furthermore, those structuralist approaches within the social sciences that are underpinned by Saussurian ideas on language and identity (Saussure, 1971) tend towards an ahistorical viewpoint and present the 'human agent' as the 'subject'. Saussure coined the term 'semiology' to describe a 'new science' which would be a part of social psychology: "Linguistics is only a part of the general science of semiology; the laws discovered by semiology will be applicable to linguistics, and the latter will circumscribe a well-defined area within the mass of anthropological facts" (Saussure, cited in Hawkes, 1977, p. 123).

¹² Comte was the first to apply the methods of positivism to the study of society (Comte, 1975; Lenzer, 1975) concluding that there were binary oppositions which were both 'static' and 'dynamic' components of social existence.

In other interpretations, such as through the use of a Marxist approach (Strinati, 1995), a historical position may emerge, but only in the sense that broad social structures are located within the broad sweep of history, and without consideration of particular discourses within particular time/space through which subjectivities are constructed. Subsequently, poststructuralist thinkers attack these and similar problems of structuralism by arguing that: “All perceptions, concepts, and truth claims are constructed in language, along with corresponding ‘subject-positions’ which are likewise (so it is argued) nothing more than transient epiphenomena of this or that cultural discourse” (Honderich, 1995, p.708). Structuralist research based approaches are therefore a problem in those areas of research where the topic requires an examination of societal structures *and* the motivations and desires within the cultural discourses of human actors within those structures; traditional structuralist approaches are therefore unsuitable for such projects.

In this thesis, post-structuralism is regarded as a transformation or extension of the modernist paradigm, and not necessarily its antithesis (Gedö, 1982); it is understood as a pluralist paradigm (i.e. there are post-modernist *visions* rather than *a vision*) that opens multiple layers of interpretation and transformations in theory, the arts and the sciences (Best & Kellner, 1991, 1997). In brief, this thesis is overlaid upon structuralist thinking and incorporates, challenges and extends structuralist thought to assist the transformative process where there are no longer structures, but rather the 'shared symbolic systems' (Bourdieu, 1977a) of the new paradigm; it is a post-structuralist thesis in a post-modern age that may at times mirror the orderliness of the previous paradigm, but it will also consider the paradoxical, the dialectical and the challenging. This thesis relies upon a poststructuralist position which includes a method of analysis that is ideal for the chosen topic. To understand why this should be so, it is now important to outline the use of poststructuralist inquiry in research, and especially in health care related research.

Poststructuralist inquiry in social and health related research

Poststructuralist inquiry views language as a most powerful definer, descriptor (of conventions), and control mechanism within society. It concentrates on analyses of literary and cultural *texts* because such texts represent “a theory of knowledge and language” as different from “a theory of society, culture and history” (Agger, 1991, p. 112). The poststructuralist approach to research therefore implies an examination of plural phenomena within a fragmented arena, and as in all poststructuralist endeavours, considers language, meaning and subjectivity within a postmodernist construction (Weedon, 1987). It is the *political* nature of language within society (as texts of varying types) that lends itself to poststructuralist research (Fairclough, 2003). Discourse is a study of the language acts of everyday life; it provides an insight into the ways in which individuals, groups or structures are ‘products’ of discourses and practices that achieve an

illusion of durability either through repetition and/or a series of historical settlements (Somers, 1992).

In the majority of the social sciences, including health and health related studies, the rational and empirical philosophical underpinnings of the modernist paradigm have not been entirely abandoned. As Habermas (1971) implied, technical knowledge is still required for a great deal of modern work practices, including health care work. The use of the natural and applied sciences, and the acquisition of practical skills, remains important in medicine and nursing, even if this type of empirical knowledge has been shown to be problematic in certain areas of research such as applied ethics or in the acquisition of ontological knowledge; in such cases, post-structuralist inquiry is becoming more popular. This is because it appears to provide an adequate response to an increasingly complex modern medical environment that remains a paradoxical mixture of both the traditional (as an art) and the modern (as a science) (Cheek, 2000). Such research highlights the paradoxical, dialectical and challenging aspects of modern health care because poststructuralist research is capable of 'multi-layered' interpretations and commentaries on health care delivery; it is therefore as useful to medicine and nursing as structuralist based research, but with a different purpose and in different ways.

Irrespective of the continuing emphasis on modernist responses to problems within health care, medicine and nursing focused research, there is a gradually emerging appreciation of postmodernist research studies in those areas (Cheek, 2000; Rolfe, 2000). These studies have brought the mechanistic and rationally orientated philosophical underpinnings of both the applied and social sciences in health care research into sharper view. That such research is now being undertaken is a reflection in itself of the recognition within at least part of academia that the 'modernist paradigm' has not provided contemporary answers to a number of difficult questions about health, care and illness. Such questions include the social meaning of and assumptions about health and health care (Cheek, 1997), the professionalization of nursing through the adoption of the discourses of others (Latimer, 1995), nursing as resistance (Peter, Lunardi & Macfarlane, 2004), and critical approaches to the current health care of the older adult with dementia (Gilmour, 2001; Neville, 2005). In a number of recent poststructuralist theses, a Foucaultian analytical perspective has been employed (Gilmour, 2001; Neville, 2005), and there is an emerging interest in the use of Bourdieusian themes and theoretical ideas (Rhynas, 2005).

French poststructuralism in social theory – Bourdieu and Foucault

The 1960s and 1970s marked a period of intellectual struggle, particularly in France, a country still struggling to make sense of the events of World War Two where reason, social structure and control were clumsily adjusted and manipulated in an attempt to create a new social order. The Marxist-structuralist position that was influential amongst the French intelligentsia after the

war (a backlash against the 'pseudo-scientific' and perverted rational approaches that were characteristics of Nazism) eventually gave way to serious doubts and incredulity, and one by one detractors emerged to challenge the very idea of structuralist thinking in any of its forms. A prominent detractor was Jean-Paul Sartre (1943/1992) who dominated French (and later European) intellectual post-war debate with his powerful rejection of the philosophical shift towards analytical scientificism through his return to a philosophy of being rather than knowing, and existence, or the meaning of things, preceding essence, or the 'internal' self. Others included Baudrillard (1988), who contributed his critique of political economy; Deleuze (1977), who offered a critique of psychoanalysis; and Derrida (1976), who waged a 'deconstructionist' war in his critique of western philosophy and literature.

Foucault, a one time follower of Sartre, championed the deconstruction of the knowledge bases of modernist disciplines within the humanities and social sciences, such as philosophy, history or sociology, and the applied sciences, such as may be found within psychiatry, medicine or prisons (Hartsock, 1990). It was Foucault who argued that 'methodological scepticism' should be employed to suspend belief in the discourses of such institutions to allow other possibilities to emerge. By doing so, he contributed to discursive analysis that critiqued arguments concerning hegemonic effects and challenged modernist arguments based on rationality alone. For Foucault, the use of rationality to support or oppose certain behaviours was a philosophically double-edged sword:

All human behaviour is scheduled and programmed through rationality. There is a logic of institutions and in behaviour and in political relations. In even the most violent ones there is rationality. What is most dangerous in violence is its rationality. Of course violence itself is terrible. But the deepest root of violence and its permanence come out of the form of the rationality we use. The idea had been that if we live in the world of reason, we can get rid of violence. This is quite wrong. Between violence and rationality there is no incompatibility (Foucault, 1980e, p. 299).

Foucault was tutor in philosophy when Bourdieu was at the *École Normale Supérieure*, and in 1982, when Bourdieu was elected to the chair of sociology at the most prestigious French intellectual institution of all, the *Collège de France*, his proposer was Foucault. Hence, both shared some of their fundamental references in the intellectual field of the 50s and 60s, such as the French historian and philosopher of science Georges Canguilhem and the "sciences humaines" in general (e.g. the *Annales* school of history), as well as connections to (and later distance from) Sartrean existentialism.

Bourdieu, after Foucault and other French contemporaries of the time, emerged as a quite different kind of scholar from many of his predecessors. His philosophical approach to his work reflected at least some of the key elements that were also to be found in the works of Baudrillard, Deleuze and Derrida. For instance, there are philosophical connections between Bourdieu's and Derrida's critique of rationalist theories of language, consciousness and the logocentric nature of traditional western metaphysics. This is especially so in relation to the

many attempts by logical analysts to analyse meaning by seeking seemingly obvious similarities or connections outside a given textual context without due regard to '*differance*' or (often hidden) differences (Bourdieu, 1984; Derrida, 1982). Furthermore, his deployment of particular concepts (such as habitus and symbolic capital) to analyse culture in general are distinctly different from previous structuralist attempts to do the same. Indeed, as Calhoun (2002, p. 1) maintains:

...Bourdieu's work should be read in specific relationship to "poststructuralism"; that though Derrida and Foucault are more conventional exemplars, on purely intellectual grounds the label "poststructuralist" fits Bourdieu at least as well; and that he represents a version of poststructuralism more serious about science and social organization than other lines of work usually grouped under that label.

The connections between Foucault and Bourdieu are therefore of interest, in that although each worked quite differently from the other and produced works that are not immediately comparable, each brings an approach to contemporary sociological theory that tackles contemporary dualisms such as modernity/postmodernity, power/resistance, and economy/culture. Their ideas, either singularly or occasionally combined, are subsequently incorporated into this thesis.

Foucault – the main ideas used in this thesis

Foucault was a social theorist who made major contributions to the study of society and politics in the twentieth century. These contributions reflected Foucault's own inimitable brand of critical philosophy which he used as a means to question historical events, and his 'archaeological' and 'genealogical' methodological approaches in examining central issues of the present by deconstructing the discourses of the past, set him apart from all of his contemporaries, including Bourdieu. He has been associated with both structuralist and poststructuralist thought, although he publicly scoffed at being labelled as either because he did not wish to be permanently associated with one paradigm.¹³ In both his overall use of method and methodology, and his emphasis on the uses of power in society, he is closely associated with poststructuralist thought and its many applications. There now follows brief outlines of a selection of his main ideas that are used in this thesis.

¹³ Arguments persist about Foucault's inconsistencies (Cheek & Porter, 1997), and it could be argued that Foucault presents a structuralist position in earlier works (such as *An Archaeology of Knowledge*, 1972) when he attempts to look beyond the diffusion and uncertainty of elements of discourse in favour of finding of "a unity ... [that] resides, well anterior to their formation, in the system that makes possible and governs" (1972, p. 72).

Method

To answer the types of questions that he was interested in answering, such as how social institutions such as psychiatry, medicine and the prison system operate within society, how perceptions of sexuality have changed over time, and how the relationship between power and knowledge affects society through various discourses, Foucault delved into the past, or as he called it, into an 'archaeology of epistemes' (1972). Archaeology was an essential method for Foucault because it allowed him to operate at a level that displaced the primacy of the subject (found in both phenomenology and in traditional historical studies) and simultaneously compare the discursive formations of different periods. Such comparisons suggested that a different way of thinking in previous ages had been able to bring about alternative results (Foucault, 1970). Hence, Foucault showed that in earlier times, mad people were not locked away in asylums, criminals were punished openly, sick people were treated at home, sexual perversities were not seen in the same fashion, and the disabled were not expected to stay out of sight. In modern societies, the exclusion of the abnormal remains a crucial part of the defining of the normal. Foucault therefore argued that through the exclusion of some, the remainder is included; and even though 'the abnormal' is hidden from view, it is studied to feed our own need to know what it is to be 'normal'. Yet such knowledge, which was scientifically based and certainly 'rational' to its users (as Kuhn [1970] also maintained) was more a product of a given time rather than a gradual upwards progression towards enlightenment through the ages:

The 'sciences of man' are part of the modern *episteme* in the same way as chemistry or medicine or any other such science... But to say that they are part of the epistemological field means simply that their positivity is rooted in it, that that is where they find their condition of existence (Foucault, 1970, p.365).

For Foucault, episteme is a system of *discourses* that come to dominate a given historical era. Therefore members of society come to accept that psychologists help them to define and differentiate between sane and insane, physicians between healthy and unhealthy, and politicians or lawyers between criminal acts and non-criminal acts.

Discourse

The control of norms, or the setting of the parameters of normality and abnormality, depends upon a reliable and credible method of delivery. For Foucault, such a method was via 'discourses'. Discourses can mean anything written or spoken or visually signed, although Foucault argued that a discourse contained a set of common assumptions which, although tacit and almost invisible, provided the basis for conscious knowledge (Cheek, 2000). Discourses create frameworks for the process of discrimination between reality and non-reality, acceptable and non-acceptable, truth and falsity and therefore provide alternative viewpoints regarding (modernist) 'structures' within society. They are therefore capable of producing power, being both a product of it *and* a point of resistance:

We must take allowance for the complex and unstable process whereby discourse can be both an instrument and an effect of power, but also a hindrance, a stumbling-block, a point of resistance and a starting point for an opposing strategy (Foucault, 1979, p. 100.)

Foucault wrote that discourses should be seen as “practices which systematically form the objects of which they speak” (1972, p.49) that occur in the activities and events within society. For him, such activities tend to engender a regular or systematic effect which *constructs* an object, and/or interprets an event in a particular fashion (Mills, 1997). Foucault called primary building blocks of discourse *enonces* or *statements* or the issuing of valid and constant confirmations of knowledge by many means that eventually became ‘reliable and trustworthy’ statements of knowledge about something:

...statements are...things that are transmitted and preserved, that have value, and which one tries to appropriate...things that are duplicated not only by copy or translation, but by exegesis, commentary, and the internal proliferation of meaning (Foucault, 1972, p. 120).

For Foucault, the means whereby statements were delivered and accepted or not accepted, the relationships between statements, and the rules that govern the use of statements were of considerable importance. Firstly, he maintained that a discursive object emerges within a particular social and historical context by following certain rules. This requires a process of differentiation (such as mad – sane; normal - abnormal) and that the given phenomenon achieves an objective status (so that all can perceive it, as if for the first time, in a clear and acceptable manner). Secondly, because certain discourses are provided by formal groups such as specialists, or those with specialised or technical knowledge, the ‘objectivisation’ of the phenomena is more readily accepted (as occurs now in ‘bipolar disorders’ in mental illness, or before that, as in ‘hysteria’ in women). Thirdly, ‘grids of specification’ are developed that define and categorise the discursive object/s so that future patterns of a similar or dissimilar nature can be identified and categorised. Foucault argued that one of the main purposes of all of this was the maintenance and exertion of *knowledge/power*.

In this research thesis, all three of the above uses of statements are applicable. That is, it will be shown that there is a process of differentiation in cases involving radical parental resistance to medical advice; there is objectivisation of the phenomenon of parental resistance; and there is continuous categorisation of discursive objects (i.e. use is made of previous cases by both physicians and lawyers to maintain or seize control over the given situation involving a child’s health care).

The problematisation of knowledge and the uses of ‘knowledge-power’

Foucault challenges any notions that knowledge is objective or value free, or that it is attained in a progressive or linear fashion. He maintains that the ‘truism’ “knowledge is power” is possible only if it is also accepted that only certain kinds of knowledge are perceived as power(ful), and

therefore of use within society.¹⁴ As Foucault explains, from early years through school and higher education, a child not only learns 'facts' but *certain facts* about the human world that he or she presumes are true facts because they are delivered with authority by a powerful figure, the teacher. These 'facts' may become the building blocks for future, the means by which we define each other and our institutions:

It is not a critical history which has as its aim to demonstrate that behind this so-called knowledge there is only mythology or perhaps nothing at all. My analysis is about the problematisation of something which is dependent on our knowledge, ideas, theories, techniques, social relations and economic processes (Foucault, 1994, p. 408).

To be in a position to define others, and thereby to provide meaning to their behaviours, is a type of power. Foucault (1979) argued that because such power was exerted implicitly by the way in which discourses were formed (i.e. by 'misrepresentations' of the source of power in the guise of defining language), then, as a normalising 'power network', it is all pervasive, affecting all aspects of modern life, including the body, sexuality, the family and technology:

There is no power relation without the correlative constitution of a field of knowledge, nor any knowledge which does not presuppose and constitute at the same time power relations ...In short, it is not the subject of knowledge that produces a corpus of knowledge, useful or resistant to power, but power/knowledge, the processes and struggles that traverse it, and of which it is made up, that determine the form and possible domains of knowledge (Foucault, 1979, pp. 128-129).

Thus, when human sciences (including medical sciences) describe human beings, they also define them and members of society respond as if the dominant discourse itself is the reality by which all should accept the necessary surveillance and governance over human activities that it brings. Yet, Foucault maintains that because individuals feel repressed in their beliefs and practices by the dominant discourses of the all pervasive power network, they wish to be 'liberated' but perceive that they are held back by 'social forces' rather than by the less identifiable and covert forces attributable to the modernist development of knowledge-power. In actuality, he argued, this is not the case. It is, he maintains, a double illusion, namely the illusion of societal repression, and the illusion of inner guilt that needs to be expressed.¹⁵

For Foucault, the power associated with a power-knowledge nexus, such as is found within medical specialisation and technology is not due to physical force, which is rarely seen in that network; yet its members exhibit a powerful degree of social engineering in the forms of control and discipline. Instead, Foucault maintains, such networks have the power to create belief

¹⁴ Foucault maintained that if 'might makes right' is a presumed truism, then it is possible that the only difference between this and knowledge is power; in the latter case, physical force (as opposed to mental force) is exerted by a powerful group/minority to impose their idea of the 'right' or the 'truth' on the majority.

¹⁵ According to Foucault (1979), human beings need to express their (misguided) feelings of repression, and individuals feel the need to make 'confessions' to others, especially authority figures such as priests or psychoanalysts (*and physicians*). At the same time, they claim that they seek freedom, but only within the confines of the repression, which is a powerful illusion in itself.

because those responsible for constructing the 'truth' are the same people who claim to possess the necessary 'knowledge'. The subsequent influence of knowledge/power within societal responses is therefore an all pervasive and largely subconscious one.

Power/knowledge is therefore not an observable entity or phenomenon that 'exists' in a particular location; it exists instead within the spatial organisation of any given institution. Furthermore, power/knowledge is fluid, sometimes meeting resistance, sometimes being resistive; it moves through institutions in ways more akin to capillary action rather than a direct flow mechanism (Butler, 1990). Thus, the pattern of power evident in the relationship between physician and patient is based on a myth or an illusion; it is socially constructed, and it is both maintained and promoted by widespread social acceptance of the illusion of control, both of the self and by the state. Yet there are those who will not 'play the game', and even those who join the game but then reject the rules at some point and choose to resist. Parents who resist medical interventions face powerful forces that may seek to pre-define and *discipline* them in how they should respond to medical advice. But how is 'knowledge-power' maintained within society, and in particular, how does it operate in cases of parental resistance?

Power, knowledge and discipline

The formations of power/knowledge nexus in society require some form of discipline to maintain them. In institutions such as the armed forces, schools, hospitals and industries, a type of powerful 'science' exerts a subtle pressure. Foucault (1977) described this problematisation of knowledge using a technique which he called 'genealogy' (evoking Nietzsche's genealogy of morals, i.e. as being originally created from a collection of rather mundane and paltry ideas) and showed that a given system of thought (as uncovered by his use of 'archaeology') was the result of contingent turns of history, not the outcome of inevitable trends in the development of knowledge. These 'contingent turns' lent themselves to the maintenance of a particular school of thought, a way of viewing the world, and of course a way of converging power and status via the setting up of parameters through the means of an organised discipline – the 'science of discipline' no less.¹⁶

Foucault gave the science of discipline five principles, namely *spatialization*, the 'placing' or labelling of everyone within the structure; *minute control of activity*, for instance, as in the

¹⁶ Foucault was to comment later: "When I say that I am studying the 'problematisation' of madness, crime, or sexuality, it is not a way of denying the reality of such phenomena. On the contrary, I have tried to show that it was precisely some real existent in the world which was the target of social regulation at a given moment' (Foucault, 2001a, p.171).

use of timetables; *repetitive exercises*, which are based on the notion of ‘practice makes perfect’ as may be seen in learning the times tables, learning to type, and learning to follow orders unblinkingly; *detailed hierarchies*, as in the use of complex chains of authority to ‘keep watch’ over the lower ranks/masses; and *normalizing judgements*, or the imposition of certain ideas of normality that must be maintained when faced with any deviation. Laws, for instance, tend to punish unacceptable behaviour rather than explain acceptable behaviours (norms), and the ultimate aim of punishment through law is to control the behaviour of others. This particular aspect of social control is called *governance*. Such means of discipline through governance was for Foucault, a covert rather than overt mechanism:

...what defines a relationship of power is that it is a mode of action that does not act directly and immediately on others. Instead, it acts upon their actions: an action upon an action, on possible or actual future or present actions. A relationship of violence acts upon a body or upon things; it forces, it bends, it breaks, it destroys, or it closes off all possibilities (Foucault, 1981/2000, p.160-161).

Parents are subject to intense pressures to conform when they oppose the desires of more powerful forces within society. Such pressures are the net product of decades of social control through medicine, law and the state; and through the use of the media as a form of more generalised governance; and by a form of self control (see later discussion). However, it is perhaps the political use of power (*biopower*) that carries the greatest weight in analysis of cases of parental resistance at a health care facility.

Biopower

Foucault (1977) made a distinction between sovereignty, the traditional power of the monarch, and ‘biopower’, the modern power of science and allied discourses, as two distinctive modes of perceiving and examining the role of law within society. In his view of the sovereign mode of social structure, law and the judicial apparatus are/were hierarchical mechanisms that regulate the constitutional and organisational elements of a society. However, in the bio-political mode of social structure, law has lost its central regulatory role to various emerging scientific discourses, both bio-scientific (medicine, and biology) and social (sociology, criminology, psychology, and statistics). The forms of power associated with the ‘sciences of man’ are represented by the term ‘biopower’. Consequently, no analysis of a legal and social phenomenon is complete unless the impact of those scientific discourses upon it is taken into account.

Foucault maintained that the concept of biopolitics highlighted the notion of the role of law in controlling the social body. Hence:

It is this social body which needs to be protected, in a quasi-medical sense. In place of rituals that serve to restore the corporal integrity of the monarch, remedies and therapeutic devices are employed such as segregation of the sick, the monitoring of contagions, the exclusion of delinquents (Foucault, 1980b, p. 55).

Such a concept therefore implies that from the eighteenth century onwards (i.e. the time of the emergence and eventual dominance of biopower), the mechanisms (or *dispositifs* in Foucault's terms) of *power* and *knowledge* begin to take into account the "processes of life" and the possibility of controlling and modifying human activities well beyond previous practices (Foucault, 1984d). Control through biopower has become of increasing significance in recent times because, in medicine for instance, the patenting of the human genome or the control of life threatening processes (such as cancer) has enabled those with such power to not only control the physical body and the social body, but nature itself.

For Foucault, it was the way that humans resisted such power and control that was of the greatest interest because it presents the opportunity to propose a new ontology, i.e. one that begins with the body and its potential, that regards the "political subject as an ethical one" against the prevailing tradition of Western thought which understands it as a "subject of law"; indeed, over time, he described this dynamic as "the emergence of a multiple and heterogeneous power of resistance and creation" (Lazarrato, 2005, p.2) that sees every societal organization and regulatory mechanism as a constitutional mechanism of control that should be questioned for its effect on the "freedom" of its 'subjects' and their capacity to act upon the conduct of others.¹⁷

There is much in this thesis that directly relates to resistance that exhibits a powerful ethical position as much as political or legal ones; it offers considerable debate about the freedom or otherwise of individual parents who must choose how to proceed when they are in conflict with the social body, the values and norms of which are stored up or reinforced by powerful forms of state, societal, organisational and regulatory mechanisms. Parental freedom to choose is, however, irreversibly linked not only to ideas of *governmentality*, but also to self-control and personal identity.

Governmentality, control of the self and identity

The close relationship between knowledge and power can be considered as a merging of the discourses of the human sciences (such as psychiatry, medicine, law and others) and governance (through the use of discipline). Foucault notes that such a combination is characterised by surveillance and discipline applied to the masses: "the state is superstructural in relation to a whole series of power networks that invest in the body, sexuality, the family, kinship, knowledge, technology and so forth" (1980a, p. 122). It is the effect of some of the state's regulatory mechanisms through economic and social networks (such as medicine, psychiatry

¹⁷ See, for instance, Foucault's later works, especially the *History of Sexuality*, volume 1 (1979).

and education) that has been the source of much speculation and debate within western society in recent times (Chomsky, 2005; Clark, 2000). Yet Foucault maintained that it was not just a question of power relationships exerted by those who ostensibly held power:

Power relations are extremely widespread in human relationships. Now this does not mean that political power is everywhere, but that there is in human relationships a whole range of power relations that may come into play among individuals, within families, in pedagogical relationships, political life etc... (Foucault, 1984b, p. 434).

For Foucault, it was not so much the holding of power and the use of it through governmentality that mattered; but self-governmentality itself:

...if one understands by governmentality, a strategic field of power relations which are mobile, transformable and reversible, I think that the reflection on the notion of governmentality cannot but pass both theoretically and practically except through the element of a subject that is defined by the relation of self to self. While the theory of political power as an institution ordinarily refers to a juridical conception of the subject of law, it seems to me that the analysis of governmentality - that is, the analysis of power as a group of reversible relations - must refer to an ethics of the subject defined by the relation of self to self (Foucault, 2001b, p. 241).

Foucault's argument that we are all subject to overt and covert types of social control means that all individuals, in a process starting early in life, will identify with particular subject positions within discourses, and construct identities through them. Because individuals live power rather than have it; power is embedded within the 'texture' of their lives, and because disciplinary power is responsible for the production of certain types of subject (which frequently occurs through the 'keeping of records'), perpetual surveillance is *internalised* by individuals to produce the kind of self-awareness that defines the modern subject.¹⁸

Hence, through the central technique of constant surveillance which is initially directed toward disciplining the body ('disciplinary power'), the effect on an individual's psychological state is a "conscious and permanent visibility" (Foucault 1977, p.201). These aspects of governmentality and self-discipline are explored within this thesis. It will later be suggested that parents are not entirely 'free' to choose as they deem fit for their children in all aspects of daily decision making, let alone those aspects concerning their own children's health care. Such overt and covert control of parental choices is therefore presented later as both a societal and individual phenomenon that significantly affects all parents, and not necessarily those who must make profound decisions concerning the acceptance or otherwise of medical advice. In this regard, the notions of *conformity* and *resistance* are of particular importance, not as a seemingly isolated occurrence, but as a more widespread social phenomenon.

¹⁸ In this, Foucault emphasises the role of juridical power inasmuch as it is thought to operate upon an already constituted individual response. That is, individuals are constantly under supervision and therefore constantly being reconstituted within society. There is therefore, no particular fixed individual identity to challenge through the law, merely a responsive but self aware subject (see also Chapter Five).

Resistance and conformity

Resistance and conformity are key features of Foucault's ideas, especially within his ideas on the power-knowledge nexus in society (1973, 1977). He argued that power, which always exists in relationship with knowledge, tends to meet with resistance, and therefore resistance is a necessary element of power itself. In effect, power is fuelled by resistance; and therefore without resistance, power fades from view. Foucault applied his analysis of disciplinary power, which is focused on individual behaviours, to mental institutions (1973), medical establishments (1975), and prisons (1977) suggesting that we now have what he calls a "disciplinary society" (1977, p.216). Yet, within such a society, many willingly conform to the operation of power. This is because, as Foucault maintains, power is productive; it produces bodies that are docile, and therefore useful. The conforming prisoner, patient, schoolchild or soldier is thus the product of a desire for particular identities and/or outcomes that are considered to be beneficial both to the individual subject and to society as a whole. Subsequently, people conform to and put up with, for instance, medical treatment because they seek cure or recovery. In this guise, power is most powerful when it is invisible; it extracts voluntary compliance to a particular disciplinary regime through well established sets of understanding about appropriate ways of acting, interacting and producing 'the body' in a given situation. Thus, power exists on multiple levels and includes the fluctuating practices of conformity and resistance throughout all of society. Yet, Foucault explained that power always tended to meet resistance, and that power and resistance were related to the potential for agency; that is, resistance co-exists with power within agency, and is always an ever present possibility in fluctuating situations of power-control-response possibilities. As Foucault (1979, p. 96) concludes:

Hence...the points, knots or focuses of resistance are spread over time and space at varying densities, and at times mobilising groups or individuals in a definitive way, inflaming certain points of the body, certain moments in life, certain types of behaviour.

Subsequently, resistance may be seen as an element of any relationships within society, but so might conformity, which Foucault maintains relates closely to 'care for the self' which suggests that although 'power creates its own resistance', each individual also subtly responds to the 'power of the norm' (Foucault, 1977). Hence, societal norms set both what is internalised *and* what is transgressive, and each individual responds according to both these self surveilling norms within a given society.

Yet Foucault was challenged for the apparent notion of conforming passivity within the subjects of power, and for the (mis)perception of power as a largely negative force. Foucault replied that conformity and resistance are not unusual responses, but part of the everyday practices of the exchanges of power between everyone. In this, power operates on a 'micro-political' level involving forms of collective, interpersonal discipline and self-discipline. Within the wide uses of power, there co-exist the elements of not only surveillance but also of (self) control and conformity:

He who is subjected to a field of visibility, and who knows it, assumes responsibility for the constraints of power; he makes them play spontaneously upon himself; he inscribes in himself the power relation in which he simultaneously plays both roles; he becomes the principle of his own subjection (Foucault, 1977, pp.202-203).

Accordingly, both the elements conformity and resistance co-exist in each individual in a constant state of *mobile and transitory* flux within their relationships with others (McHoul & Grace, 1993). At times, one may be seen operating over the other, but in most cases, there exists a balance between the two that reflects different shades of responsiveness according to situation and disciplinary mechanisms. Yet when some parents resist medical treatments in this way for their children, they are causing a noticeable imbalance by transgressing societal norms and relationships by 'standing outside' society either temporarily or for a considerable period of time. To theoretically illustrate and frame such behaviours, this thesis also draws on the key ideas of Bourdieu, who not only provides a detailed and highly organised account of the complexities of societal relationships, but also appropriate theoretical material that helps to sociologically 'frame' some of Foucault's ideas within this thesis.

Bourdieu – the main ideas used in this thesis

Bourdieu's sociology in general can be characterized as an investigation of the pre-reflexive conditions that generate certain beliefs and practices in capitalist systems (Bourdieu & Wacquant, 1992). However, unlike Foucault, Bourdieu's overall approach to a study of social relationships and the discourses within, is to offer a method of analysis that is based on empirical rather than 'archaeological' or 'genealogical' methods, *and* a theoretical perspective that develops major and enduring sociological concepts to guide future analysis of the social world (Bourdieu, 1993).¹⁹

Method

Typically, in his theoretical approach, both individual experiences and broader social conditions are given prominence, and his work recognizes that in different societies there are many different types of cultural groups (Bourdieu, 1984). Bourdieu conceptualises such assumptions as *habitus*, which can be defined as a system of durably acquired schemes of perception, thought and action, engendered by objective conditions but tending to persist even after an alteration of those conditions. He sees habitus as the key to the reproduction of class behaviours because it is what generates the regular practices that make up social life. Habitus is the product

¹⁹ It is maintained that Bourdieu was essentially a structuralist. However, it may also be argued that although he analysed inequality and class distinctions at a structural level, he never succumbed to the 'objectivist illusion' of structuralism (Lechte, 1994).

of social conditioning and so links actual behaviour to class structure. Similarly, his work recognizes that different sets of social "rules" apply in different contexts, which he refers to as *fields*. To gain entry to a field or to participate in activities within a field, different forms of resources are drawn upon, or contributed. Such resources are characterized by Bourdieu as *capital*. Capital can take many forms including symbolic, social, cultural, or material use of resources. Such 'capital' is created through social exchanges, as "day-to-day" work is undertaken and is drawn upon to gain entry to or to navigate social fields. For instance, the media represents a powerful source of symbolic power in society, influencing as it does both cultural and social capital (Bourdieu, 1991, 1998b). Bourdieu's programme of research focused attention on the social processes and societal practices that shaped inter-group relations. A central concern was to make visible the ways broader societal practices, sanctioned in policy and tradition, structured relationships and shaped experiences of those largely outside of the formal institutional discourses, such as the poor, immigrants, women, and/or youth. As such, a Bourdieusian perspective, i.e. one that incorporates a conceptual framework that specifically analyses the culturally powerful and the less culturally powerful enables an analysis that can refine and extend our understandings of links between health care providers and health care recipients.

Bourdieu considered "...structure as a product of human creation, even though the participants may not be conscious of the structure" (Rubel & Rosman 1996, p.1270). In this claim, Bourdieu maintained that the structuralist notion of the universality of human thought processes (i.e. as a creation of the human mind that tended to impose certain 'structures' on observable events) was misguided, and that it was really 'dominant thought processes' within society that tended to influence how people were perceived and also acted. In response to this problem, Bourdieu maintained that any observer (of others in another culture) should attempt to describe that culture in a truly objective fashion rather than impose the observer's perceptions onto the analysis in progress, as other structuralist researchers had done previously. Of course, such apparent description always brought into focus the problem of 'structuring' the observed by the observer; which for Bourdieu, represented a major point of concern, i.e. of how to remain objective without imposing one's own viewpoint. For Bourdieu, this problem was not insurmountable, and he attempted to deal with it by reference to reflexivity.

Reflexivity

Bourdieu's use of "epistemic reflexivity" is a crucial underpinning of his work that supports his claims to provide distinctive and scientific knowledge of the social world. Indeed, as Wacquant (1992) noted: "If there is a single feature that makes Bourdieu stand out in the landscape of contemporary social theory, it is his signature obsession with reflexivity" (p. 36). Bourdieu considered that his approach to reflexivity counteracted the claim that sociological texts

habitually reflect a more sociological, individualistic, and narcissistic collection of viewpoints; Bourdieu therefore sought to be epistemological, collective, and objective in his approach to reflexivity in his research (Maton, 2003). He maintained that it was through his particular approach to reflexivity that it was possible to offer both valid and reliable research in the social sciences. In this claim, he considered that such objectivity was only possible through firstly identifying the researcher's own position within the field of study. As Formosa (2005, n.p.) states:

This emphasis was based upon Bourdieu's (1988, 1989c) belief that the most insidious bias that a sociologist can make is to assume a scholastic stance that causes him/her to misconstrue the social world as an interpretative puzzle to be resolved, rather than a mesh of practical tasks to be accomplished in real time and space. This 'scholastic fallacy' eventually leads to disfiguring the situational, adaptive, 'fuzzy logic' of practice by confounding it with the abstract logic of intellectual ratiocination.

Hence, in Bourdieu's approach, the researcher always fully recognised the subjective meanings that he or she brings to the field of study by inserting it within the study. Bourdieu also stressed that the relationship between the researcher and the researched participant should be made explicit in the research. Such manoeuvres may not satisfy all requirements of a poststructuralist viewpoint, however, but the attempts made by Bourdieu to at least address the problem of reflexivity earned him a position as a poststructuralist within a structuralist world.²⁰

In response to the limitations of structuralist research within the social world, Bourdieu suggested a quite different way of proceeding using a method and theory of practice that recognised that individuals in society were not fully represented by merely aggregating their behaviours in a descriptive fashion, but by discovering and recording the influences of cultures, traditions and objective structures on their behaviours. To achieve this, Bourdieu set out a conceptual model that incorporated all of the sociologically relevant concepts such as 'field', 'capital' and 'habitus' that he found to be at play within society.

Field

Much of Bourdieu's work concerns the independent role of educational and cultural factors within a given frame of analysis. Instead of analysing societies in terms of classes, as Marxist analysis dictated, Bourdieu used the concept of field which he saw as the social arena where people manoeuvre and struggle over desirable resources. A field is therefore a system of social positions, structured internally in terms of power relationships. Different fields can be quite autonomous and more complex societies have more fields. Structures within each field are not only statically observable, such as institutions, authorities, activities and others, but they are

²⁰ In fact, Bourdieu represented a 'third way' between modernist rationalism and postmodern relativism (Calhoun, 1995; Harrison, 1993).

dynamic as well. That is, the effects of the field can be recorded as they influence both the competitive actions of those within the field and the effects of those actions on others who are outside the field (Bourdieu & Wacquant, 1992). In essence, fields are sets of relations in society rather than physical entities, and therefore the relationship between field and *habitus* (see later discussion) is determined by practices; in this way, fields condition habitus, and habitus inform fields.

Hence, field is an essential element in any social study, as it frames the relationships of those within the field, and the ways in which issues within the field are presented in a wider sense. Bourdieu's use of field allows the relationships between individuals and the structures that surround them to be made explicit. But how are the actions of those within a field to be interpreted, and how exactly is the interplay between individuals and structures to be represented? Bourdieu's response was to maintain that individuals use different forms of 'capital'. It follows then, that in a study that examines parental and medical manoeuvres over the use of resources from the viewpoint of a system of social positions that are structured in terms of power relationships, there is much to be said about field dynamics. This is certainly the case when doctors and parents have to reach an important agreement together regarding the proposed medical treatment of a seriously ill child. It is then that the concept of social *capital* becomes one of major significance.

Capital

Bourdieu (1984) explains the concept of *capital* in social contexts by maintaining that capital involves several fundamental but beneficial categories that can be exchanged and transformed into one another according to usefulness or desirability. These categories are as follows:

Cultural capital - This arises from prestigious cultural goods that are produced within a given social field; for example, positions within cultural institutions such as universities. Cultural capital therefore represents forms of knowledge, skill and education. Bourdieu elaborated upon this notion by describing cultural capital in three forms: i) the *embodied state* in which culture is literally "embodied" through ways of speaking (which denotes class or geographical origin, or even a scholar's internalisation of knowledge during the extended period of a doctoral research program)²¹; ii) the *objectified state*, when culture is made manifest in objects, such as paintings or books, and iii) the *institutionalised state*, in which cultural status is recognized and legitimized by institutions, as a degree conferred, or a prestigious appointment held (Bourdieu, 1986).

²¹ See also later discussion concerning 'bodily hexis', Chapter Six, pp. 156-157.

Social capital – This arises from networks of social relationships and influence; whereby resources are based on group membership, relationships, networks of influence and support that people can utilise by virtue of their social position.

Economic capital – This is command over economic resources (cash, assets, money).

Symbolic capital – This represents the types of possessions, ideas, social prestige and/or honour that are internally valued.

Bourdieu's theory is one of class reproduction, that is, of how one generation of class ensures that it reproduces itself and passes on its privileges to the next generation (Bourdieu, 1984). According to Bourdieu, the main source of modern success in this regard is education, where what is necessary for educational success is a whole set of cultural behaviours. Children of middle and upper class families have learned these behaviours, but their working class peers have not, therefore the former are able to succeed within the educational system and reproduce their class position. Working class children do not see this success as a product of the structuring structures of an education system that systematically advantages children from middle class backgrounds; instead, they regard the success of the middle class children, and their own failure, as a legitimate consequence of their status, and therefore natural. Bourdieu sees the legitimation of cultural capital as crucial to its effectiveness as a source of power. Indeed, it is seen by Bourdieu as *symbolic violence*, i.e. a type of 'soft violence' which is exercised upon a social agent with his or her complicity (Bourdieu, 1977a, 1991). That is, people come to experience systems of meaning (culture) as legitimate, and there is an ever present process of misunderstanding or misrecognition between social classes of what is really the case. A key part of this process is the transformation of people's cultural habits or economic positions into symbolic capital that has legitimacy that is seen as real. *Symbolic capital* is therefore nothing more than economic or cultural capital which is acknowledged and recognized and then tends to reinforce the power relations which constitute the structure of social space.

Bourdieu's ideas on cultural and social capital may be used to frame or sometimes underpin a significant amount of debate and critique of parental relationships with members of the medical profession. These relationships, it will be maintained, are dependent on the embodied state (i.e. medical knowledges), the objectified state (i.e. control over medical technologies) and most certainly the institutionalised state (i.e. the hospital). Furthermore, social capital is later shown to play a vital role in the relationships between the two parties, namely one that generally works against parents but for physicians. Such a claim may be further supported by an appeal to *habitus*.

Habitus

According to Bourdieu (1990b), *habitus* is:

The system of durable, transposable dispositions, structured structures predisposed to function as structuring structures, that is, as principles which generate and organize practices and

representations that can be objectively adapted to their outcomes without presupposing a conscious aiming at ends or an express mastery of the operations necessary in order to attain them. Objectively 'regulated' and 'regular' without being in any way the product of obedience to rules, they can be collectively orchestrated without being the product of the organizing action of a conductor (p. 53).

Bourdieu tended to bypass a Marxist approach (that would normally examine social totality as a global alternative to inequality) by exploring the *cultural* domination of capital through habitus and not just economically defined class arrangements. He performs a similar manoeuvre around Gramsci's critique of the separation of hegemonic forces within the state and society (1971).²² For Bourdieu, habitus is a culturally orientated term given to those processes that occur and are adopted through upbringing and education. There are two kinds of habitus, namely class habitus and subjective habitus. Together they represent the total ideational environment of an individual which includes his/her beliefs and dispositions, and prefigures everything that that person may choose to do.

The concept of subjective habitus challenges the concept of unfettered free will, in that within a certain habitus at any one time, choices are not limitless; instead there are limited dispositions, or states of readiness for action. A person is not an automaton, for there is flexibility in a habitus, but neither is there complete free will. In nearly all instances, habitus is an unconscious, taken-for-granted phenomenon that every individual presents to the world. As Bourdieu (1992) noted, "when habitus encounters a social world of which it is the product, it is like a 'fish in water' . . . it takes the world about itself for granted" (p.127).

A central argument in the concept of habitus is that it suggests that there are a number of options for action that a person could take, but their upbringing and education presupposes them to make decisions based on certain choices and exclude others. In normal social situations, a person relies upon a large store of scripts and knowledges, which present that person with a certain picture of the world and how she or he thinks to behave within it. As a result, certain choices are likely to be made that reinforce a person's identity by producing the least amount of ontological stress to the individual. A person's habitus cannot be fully known to the person, as it exists largely within the realm of the unconscious and includes things as visceral as body movements and postures (termed *bodily hexus*), and it also includes the most basic aspects of thought and knowledge about the world, including about the habitus itself.

It is the concept of habitus that links together not only all social texts, but also ideas concerning the self, self regulation and *identity*. The latter is a distinctive feature of Bourdieu's

²² Gramsci is renowned for his concept of cultural hegemony as a means of maintaining the state in a capitalist society. He argued that a diverse culture can be ruled or dominated by one group or class, and that everyday practices and shared beliefs provide the foundation for complex systems of domination (Gramsci, 1971).

approach towards how individuals interact within a social field, and serves as a sociological framework in which Foucault's notion of individual identity may be explored.

Social identity

Bourdieu (1985) argued that within a multi-dimensional social field which is defined by socially relevant variables, those individuals that occupy similar positions can be considered together as 'classes'. Therefore, he argued, such classes hold a common social identity that is socially constructed through which the members of that class identify their own position, and are identified by others, in the social world. They not only hold this view, but they constantly reinforce it by automatically manipulating their physical and social surroundings to maintain it within social fields (which are in turn subject to conscious and unconscious variables, or habitus, that serve to maintain them).

In Bourdieu's view, the process is neither objectively determined nor a matter of free will; that is, the construction of social identity occurs primarily through internalised and routinised daily practices rather than any deliberate conscious intent. Indeed, as Bourdieu (1990a) later makes transparent that classes, and thereby identity, clearly exist in objectively delineated spaces that may be observed, measured and recorded. Such identities may therefore be observed in a variety of ways that include, for instance, the different uses of vocabulary, or recognizing differences from those designated with other identities, or being identified by others according to the desirable identity label, or by identifying themselves within a certain category (Bourdieu, 1984).

The theoretical connections between Bourdieu and Foucault

There are as many similarities as differences between Bourdieu's and Foucault's thinking. For instance, both Bourdieu and Foucault were interested in the ways that identities were shaped by outside forces. For Foucault, it was discourses and technologies of power; for Bourdieu, it was the fields in which people interact. Furthermore, Bourdieu's intellectual response to the value of science and scientific methods differed crucially from Foucault's because Bourdieu accepted the challenges of empirical research rather than scorned them. He saw them as the best means for challenging established ideas and seemingly self-evident social relations (Calhoun, 2003). Bourdieu's studies eventually mirrored Foucault's work in moving beyond structuralist notions of Cartesian dualism concerning the individual knowing subject and into a poststructuralist examination of the meanings attached to individual identities. He also shared with Foucault a suspicion of purely actor-centred (e.g., Sartrean) accounts of social life and, like Foucault, emphasised the importance of recognising the different ways in which power is embedded in social relations. Bourdieu's theory relates to his (left wing) politics far more openly than perhaps Foucault's does; his notion of power always had more to do with an interest in the agents wielding and benefiting from it (Bourdieu, 1998a).

Both Foucault and Bourdieu pursued the theoretical couplet of knowledge/power in different ways to great effect. For instance, Foucault maintained that law has the power to formalise disciplinary (but historically contingent) power claims which are themselves universalised as the 'truth' of science; In turn, science is conditioned upon historically contingent constructs as to what 'legality' is, and therefore power is exerted through particular discourses at the expense of others (Foucault, 1977, 1980a). Bourdieu pursues the power/knowledge couplet by maintaining that capital is not granted a solely economic meaning, but essentially as a resource which yields power through a variety of representational means within a theory of symbolic power (Bourdieu, 1984, 1987a). Yet Bourdieu differed from Foucault in arguing that knowledge not only fortifies the hierarchies of the social world but also can be an effective part of the struggle to change that world. For Bourdieu, and unlike Foucault, that struggle need not be simply a matter of power but can be a matter of knowledge which transcends power. However, for both, power (and therefore resistance) of a kind within relationships was a central concern that they tackled in different and yet predominantly post-structuralist ways.

Subsequently, whilst it is evident that Foucault and Bourdieu differed considerably terms of object (e.g. domination or power) and in terms of references (or philosophical ways of thinking), they shared common ground in their extensive works concerning knowledge/power, and the critique of the notion of the ostensible neutrality of researchers. Most noticeably of all, Bourdieu's ideas were constructed around 'structured structures', but Foucault's ideas were a revealing deconstruction of these structures themselves.

Researching parental resistance

Method

Discourse analysis was chosen as the method for performing the research. This choice was based on two fundamental ideas concerning discourse analysis that served to progress the aims of the research. The first idea is that language has meaning that is both historically and socially situated (Cheek & Rudge, 1994). That is, the ways of communicating through a variety of *texts* (such as newspapers, books, journals, interviews, recorded observations, drawings and film) are also ways of supplying meaning at a given time and within a given group or population. Secondly, discourse analysis remains firmly fixed within [con]texts; that is, within social, cultural, political and historical realms, and not, as is commonly seen in generally modernist scientific approaches, by disengaging from or minimising the effect of context.

Discourse analysis is not necessarily one method but many (Burman & Parker, 1993) because it represents an often multi-disciplined and diverse approach to research that could include ideas from philosophy, linguistics, anthropology and sociology within a wider poststructuralist methodology. Nevertheless, it is formulated around a central idea, namely that:

A discourse is a way of speaking, but a way of speaking that is connected to the wider social cultural and historical matrix of any particular situation. A particular discourse reinforces a certain way of seeing the world, limiting what we can see and say. It at once produces and reinforces a particular world view and marginalizes others (Davis & Dew, 1999, p. 162).

However, in all variants, the chosen variation of discourse analysis uses a 'poststructuralist lens' to interpret 'texts', which may take on many forms; as many perhaps as there are discursive elements (that sometimes are in conflict or overlap each other). This diversity does not mean a fragmentation or a 'free for all' however, because as van Dijk (1997, p.1) indicates, "the whole point [of an analysis of discourse] should be to provide insights into structure, strategies or other properties of discourse that could not readily be given by naïve recipients".

The main approach to discourse analysis employed in this thesis is traceable to continental social philosophy and cultural analysis (as represented by the works of Foucault, 1970, 1972, 1973, 1975, 1977, 1979, 1980a, 1980b, 1984b-e, and Bourdieu, 1977a, 1984, 1988, 1990a, 1990b, 1991, 1992, 1993, 1998b). Such works show how institutions, practices and individuals may be seen, and/or see themselves, as a product of sets of discourses. For example, the role of the nurse in modern society may be represented by the 'vocational/good woman' discourse; the 'handmaiden to the doctor' discourse, the 'skilled professional' discourse; or the 'specialised technician' discourse (Chiarella, 2002). In this research project, discourse analysis is the method by which a particular discourse (i.e. parental resistance) is examined to enable access to the ontological and epistemological assumptions within sets of related discourses.

In a study of parental resistance, where parents refuse medical advice for their children, and the law and sometimes the media becomes involved, the use of language, textual and *contextual* interpretations are of considerable importance. Of equal importance is the need to represent a *range* of discourses and discursive practices that exist between medical 'specialists', those that are associated with them (nurses), members of the public (parents), the media and the legal system. This is because of "the linguistic and visual representations of medicine, illness, disease and the body in elite and popular culture and medico-scientific texts [that] are influential in the construction of both lay and medical knowledge and experiences of these phenomena" (Lupton, 1998, p.78). In this study, a discourse analysis using Foucault's concepts of discourse, power/knowledge and resistance, combined with associated ideas taken from Bourdieu's concepts of habitus, capital and field (in a 'weft and weave' approach), provides the main theoretical framework for analysis and discussion.

Design

For the purposes of the study, material was gathered from a range of textual sources including media, legal and the 'established' academic literature on parental resistance, as well as information gathered from interviews with parents, doctors and nurses. Personal texts were seen as crucial to the research because they helped to represent the use of language and its implied

meaning at an individual level; public texts represented material gathered to illustrate the wider ideological use of language and the socio-political context of meaning.

The different texts used in the research represent a variety of discourses that reflect the discursive elements of power, discipline and social control that circulate within the fields in which they are embedded. The personal was also found to be political - in ways that reflect Foucault's (1977, 1980a, 1991b) analysis of power as a mobile and constantly shifting set of force relationships that emerge from *every* social interaction and thus through 'every capillary of the social body' itself. Conversely, the socio-political was found to contain several aspects of the personal - as maintained by Bourdieu (1984), in as much as there are social patterns relating to class, gender and status that pervade the individual lives of all.

The uses of public texts

The media

Relevant newspaper articles (either in print or web based) provided the majority of media texts for analysis²³, many of which came from the *New Zealand Herald*, which is the country's most widely read daily newspaper with readership figures of 522,000, which is more than double the nearest rivals (AC Nielsen, 2000; Newspaper Advertising Bureau, 2000). A collection of articles about parents who resisted medical advice or treatment for their critically ill child quickly grew as the research progressed, and reports of court cases, radio commentaries and television material, web based articles, and articles from national magazines were added. Such sources rarely dried up during the entire course of the research, although media interest was most intense around the times of relevant court hearings or trials. At one point, after my interest in researching such cases was reported in a daily newspaper (Mold, 2000), I joined the media debate and contributed to media texts by becoming involved in a radio response to the comments from the New Zealand Commissioner for Children about resisting parents and an appropriate medical response (Woods, 2000). Comparative international media material was also obtained via the internet for the research, and was incorporated into the research as required. Nevertheless, local material remained the main focus of the media related analysis as the thesis progressed. The degree and style of media related material was important to the research because it was through these channels that many members of the public and health care professionals came to know about and interpret the details of the cases as they were presented in court (Lupton, 2003). In this thesis the media were seen as a major contributor to discourses

²³ More examples of these articles are listed in Appendix Six.

about parental resistance that attempted to frame the debate and influence audience perceptions of particular cases (see Chapter Four).

The judiciary

Relevant court reports and proceedings including radio and other media coverage of legal proceedings were obtained during the course of the research. Opinions from lawyers or legal commentators and/or state actors were also sought during the course of the research for this thesis. An example included an interview that I performed with the Health and Disability Commissioner of New Zealand. As was the case in media texts, some legal material and/or commentary was also taken from international sources. Another useful source of information was obtained from a 2002 radio interview between doctors, lawyers and legal experts in Australia and New Zealand that covered cases of radical parental resistance in those countries (Carrick, 2002). All of these texts were incorporated into the thesis in its final form (see Chapter Five).

Established literature

Selected textbooks, journal articles, web based commentaries, theses, seminar and conference presentations, reports and guidelines were examined for this research project. Very little of the examined literature provided a discourse analysis of parental resistance or dealt with the issue from a 'consumer' or parental perspective. This served to spur on the research rather than detract from it, and gave impetus to the idea that the research should include interviews with parents, doctors, nurses and other key actors in the field.

A number of academic and professional texts were influential to the development of theoretical frameworks for the thesis. Useful texts were incorporated in the thesis from a wide range of sources and disciplines that included philosophical texts (Armstrong, 1992; Foucault, 1970, 1972, 1973, 1975, 1977, 1979), texts dealing with moral philosophy and/or bioethics (Campbell, Charlesworth, Gillett & Jones, 1997; Milo, 1986); medically orientated texts (Brody & Engelhardt, 1987; Eisenberg, Kessler, van Rompay, Kaptchuk, Wilkey, Appel. et al., 2001; Ernst, 2001), nursing texts (Bishop & Scudder, 1986, 1990, 1991; Broome, Knafl, Pridham, & Feetham, 1998; James, Ashwill & Droske, 2002), sociological texts (Bourdieu, 1977a, 1984, 1988, 1990a, 1990b, 1990d, 1992; Lupton, 1995, 1999, 2003; Swartz & Zolberg, 2004), social science research texts (Cheek, 2000; Parker, 1992) and other interdisciplinary texts of a more indeterminate nature (Best & Kellner, 1991; Kuhn, 1970; Mezirow, 1981, Schön, 1983) An overview of the uses of established literature is provided in Chapter Three of the thesis.

Self involvement in the literature

I attempted to contribute to the literature during the course of the research, usually by presenting exploratory and rather elementary articles or seminar presentations designed to increase overall interest in the research topic, and in my own research in particular. For instance, an early

attempt at a 'work in progress' article, partially to encourage more nurses to volunteer for an interview, partially to attract more comments from nurses in general, and partly to help sort out my preliminary ideas in writing, was published in 2001. Regular presentations were offered of the gradually emerging conceptual elements and divergent discourses of the research at conferences, seminars and in journal articles (Woods, 2000a, 2001a, 2001b, 2002, 2003, 2005, 2006a, 2006b). I also promoted the research project in the media in its initial stages, mainly to inform the general public and health professionals of its existence, and to encourage public involvement, however small (Woods, 2000b, 2000c, 2000d).

The use of interview based texts

Ethical committee approval and use of information

The ethics approval period lasted about a year. The study was examined and approved by Massey University Human Ethics Committee and the Auckland Human Ethics Committee. It was also slightly modified three times, the modifications being largely involved in making sure that the Information Sheet would be fully understood by all participants. The Information sheet for parents was therefore different in detail from the one used for doctors and nurses (see Appendices 2 & 3). Anonymity and confidentiality were guaranteed. This thesis has been prepared from the completed research. Throughout the research period, academic papers, journal articles and conference material was produced, and it is expected that similar activities will continue after the thesis is released. All research participants have been offered a written report of the study, and have been invited to view the finished thesis. It is anticipated that advisory notes, guidelines, protocols or standards for medical and nursing staff may result from this study.

Following ethics approval semi-structured, conversational interviews were conducted with parents, doctors and nurses, and themes relating to parental resistance were explored. Themes central to the aims of the research that I was interested in pursuing included:

- The impact of critical situations on the parents of young children and on the health care staff.
- The experiences and views of parents in the determination of their own child's medical treatment.
- Perceptions about the limits of patient/parent/guardian self-determination in health care institutions.
- Talk concerning the threshold for the engagement by medical staff in paternal activities that include legal actions.
- Consideration of the consequences of health care disputes that lead to parental resistance when seriously ill young children are involved.

All interviews conducted for the purposes of this research included discussion of disputed treatment decisions under difficult circumstances. These circumstances included:

- A seriously ill child (between the ages of approximately 1-7 years preferred²⁴).
- A proposal or actual medical treatment in response to the illness of the child.
- Doctors' perspectives on parental resistance to such proposals.
- Nurses' perspectives on parental resistance to such proposals.
- Parents' perspectives on their responsibilities of care, especially those elements where they disagreed in some way with the proposed treatment of their child.

Procedures for recruiting participants and obtaining informed consent

As previously noted, it was necessary for the credibility of the research to examine a range of publicly sourced texts, but also individualised and personal interview material as well. Interviewed participants included five nurses, five doctors and five parents. One other interview, representative of a legal or State perspective was given by the Health and Disabilities Commissioner of New Zealand. The initial groups (i.e. parents, physicians and nurses) were chosen to ensure that a diversity of perspectives was presented, and considerable effort went into distributing a letter of introduction (Appendix 1) and finding suitable participants. The people interviewed for the thesis provided a 'purposive sample' (Coyne, 1997) of those involved in the field of study. The criteria for inclusion was a minimum of two years experience in the area of paediatric oncology for doctors and nurses (later changed to paediatric medicine or nursing), and experience of caring of a seriously ill child (an age range of 1-13 years was accepted) for parental involvement (Appendix 2 or 3). Each interview varied in actual length, some lasting about an hour, others two hours. Overall, the shorter interviews were obtained from physicians, the longer ones from parents.

Doctors and nurses were recruited by the distribution of the letter of introduction within their place of work. Originally the staff of a specialised Paediatric Unit within a large city hospital was selected for this task, but later because of difficulties recruiting volunteers, staff from another large Paediatric Unit within a second large hospital in the same city was invited to participate.²⁵ After volunteering to be interviewed members of both groups received the appropriate information sheet. Parents were recruited through the use of a number of agencies

²⁴ This enabled the research to concentrate upon the issue of parental decision making rather than the even more convoluted issue of 'child-parent' decision making. This is not to say, however, that this issue was entirely ignored in this thesis.

²⁵ This is because the first request for nurse participants at one particular hospital was fruitless. It has since been suggested that at least one important reason for this was a recent incident at the unit involving a seriously ill child and issues with his/her parents that was still painfully fresh in the minds of the nurses.

such as local community and hospital based support agencies that provided them with the letter of introduction; and they then volunteered after receipt of the information sheet. All participants signed a consent form after reading the Information Sheet and having the details of the study explained to their satisfaction (Appendix 4).

Finding participants

Material for analysis from interviews with parents, doctors and nurses was collated over several weeks and in three distinct stages between 2001 and 2003. The interviews were arranged only after a period of considerable difficulty in actually recruiting enough volunteers to be interviewed. Early attempts in the first stage tended to stall quickly. A visit to a specialised Paediatric Unit in Auckland to hand out letters of introduction and information sheets to medical and nursing staff and discuss the research with them as required yielded no immediate response and only later, one interview (a physician). No nurses on the visited unit wished to be interviewed, although one (who no longer actually worked there) did initially volunteer, but then later withdrew. The reticence of the nurses to be interviewed was a surprise at the time, but on reflection, it is likely that background pressures and recent 'in-house' difficulties (see footnote) were too great a distraction for them. A possible interview with a parent resulted in a visit to an empty house, and another turned out to be a useful mistake, ending up as an informal two hour lecture on the evils of modern medicine from a couple deeply committed to alternative medicine and health practices. It must be said, however, that this interview was influential in formulating an early idea that perhaps the parameters of the research were too limiting. This later proved to be the case. I therefore remain grateful to this couple for their input, however informal at the time.

A second attempt to recruit participants in the same city in 2002 yielded better results. By this time, local assistance from nursing colleagues and a community agency for parents to distribute the letters of introduction had been offered and gratefully accepted. This yielded about a third of the final number of interviews, one parent, three nurses, and one physician). Even though the introductory letters and information sheets were widely distributed, the numbers of potential interviewees was still insufficient. In light of this, members of another Paediatric Unit at another hospital in the selected area were given introductory letters via the help of a small group of interested medical and nursing administrative staff. The response here was much better, and seven interviews followed, five nurses, one doctor and one parent. There was now, finally, a viable amount of interview material to analyse. Following a few phone calls and e mails, a fourth and final attempt at recruiting in the city a few months later yielded the remaining participants (a total of five parents, five nurses, and five doctors).

Contextual and procedural elements

The interviews with physicians seemed to be the least tension free for myself as the interviewer, followed by the parent interviews, and ending up with largely very relaxed interviews with nurses. Most of the interviews with the physicians were 'slotted in' between one situation and another in their 'busy days', and nearly all were within their place of work, usually in their own office. The nursing interviews were often carried out on the nurse's day off, at her or his home, and over several cups of tea or coffee. Parental interviews were carried out in a place of their choosing, and varied from at home, at work, or even on one occasion, in a hospital side room. The tensions that I experienced at the interviews are quite likely unsurprising, particularly in light of differences in habitus and field (Bourdieu, 1984). That is, the nurses knew that I was 'one of their own', as we shared a common language and general background in a relaxed atmosphere; the physicians knew that I wasn't 'one of their own', and were generally 'pressed for time' within what was mainly in their chosen context, i.e. at work; and the parents were probably unsure about whether or not they really wanted to recall in depth what, for most of them, was a very painful experience. Subsequently, the parental interviews, wherever they were held, all tended to carry a high emotional charge for both interviewer and the interviewee.

The questions asked followed a semi-structured format, generally guided by the preliminary questions. Separate information sheets containing examples of these questions were developed for parents and health professionals (for full details, please refer to Appendices 4 or 5). Questions were also adapted during the interviews as participant needs were considered.

For parents or guardians the general approach to questions asked included the following:

- "Tell me about your child's illness. How was it identified and what happened?"
- "When your child was seriously ill, do you remember an incident that, in your mind, marked a major turning point in the treatment of your child?"
- "Can you recall your input at that point in ways of decision making and negotiating with the medical staff about your child's proposed treatment?"
- "In regard to this research, do you recall any areas that you either agreed or disagreed with the proposed treatment for your child?"
- "What, if any, do you think were the moral or ethical aspects of the situation that you have described?"
- "How did you decide which course of action would be appropriate in your response to this incident?"

For doctors and nurses, the preliminary questions asked at interview included the following:

- "In your work with seriously ill children and their parents, do you remember any general situations that marked a major change in the overall approach towards decision making of the health care team involving parents and/or their children?"

- “Can you recall your input in ways of difficult decision making and negotiating with parents/guardians about proposed treatments for children?”
- “In regard to this research, i.e. cases of treatment option disagreements between medical staff and parents/guardians, do you recall any general situations that you either agreed or disagreed with the parents over the proposed treatment of children?”
- “What, if any, do you think were the moral or ethical aspects of the general situations that you have described?”
- “How would you decide which courses of action would be appropriate in your overall responsiveness to disagreements between medical staff and parents/guardians?”

The above questions provided a framework for the interviews, many of them expanded considerably into other reflections and ideas that extended well beyond the basic set of questions. In all, the interviews provided information from which to develop conceptual ideas in the thesis, and to provide an insight into the experiences of parents, doctors and nurses in disputes involving the treatment of critically ill children.

Transcription

Two typists transcribed the recorded cassette tapes verbatim and produced a preliminary transcript; each tape was then played back with the transcript before me and corrected as required. Both transcribers complained that “doctors (and a few of the nurses) seem to use a different language from the rest of us” (or words to that effect), but they liked transcribing the parents’ tapes because they could understand them more easily. Throughout the period of transcribing and checking, I was grateful for Silverman’s (1993) observation that discourse analysis does not require quite the same precision in transcriptions that alternative forms of analysis, such as conversational analysis, seem to need. Pitch changes, emotional emphasis and pauses were not well represented in the transcripts; a problem that may never be fully resolved in such research. Changes were made to the transcribed material where particulars that may identify or indicate persons or places were noted. In all cases, such entries were disguised by replacing such items with single letters or similar codes. What resulted was a representative account of every interview, even if a few passages were difficult to follow or emotionally demanding.

Ethical concerns

This research raised the ethical issue of the rightness or wrongness of interviewing the parents who may have undergone considerable psychological trauma because of their child’s illness. Such situations could have involved psychologically disturbing and protracted disagreements between the parents, health care personnel and/or other family members. These issues, and related points, were raised in the reply to the submission of this research to the appropriate Human Ethics Committees (Chainey, 2001). Similarly, care was required when interviewing

doctors and nurses who themselves may well have faced difficult and disturbing situations when dealing with resisting parents, especially if the result was the death of a child. A great deal of care was taken to address all perceived ethical issues concerning this project. The main ethical issues arising from this project and the responses to those issues are now considered below.

Privacy Issues

The chosen city for the research operated several health care facilities, and the range of doctors and nurses that were working in the area of critical paediatric care was large enough to guarantee anonymity. Potential participants who conformed to the selection criteria were contacted and offered an invitation to participate in the research. Parental participants came from the greater city area, which included more than one million citizens. It was not the intention of the researcher to approach anyone who had already been subjected to unwelcome media attention unless that person (or persons) responded to the general request for research participants.

Informed Consent

The researcher explained the project to the participants who met the selection criteria for the study and had indicated interest following receipt of the letter of introduction. The information sheet outlining the project was then provided to all volunteers and time allocated to allow potential participants to decide whether or not to be interviewed for the research. This time varied between a few hours in some cases (some nurses and doctors) to many days or even weeks. A final explanation of the research was given at the place of work, or in any venue chosen by the participants. Only when all details had been fully understood did any participant sign the consent form and a date and time was set for the interview.

Confidentiality and use of results

All interview material was coded with pseudonyms instead of real names, and the code list stored separately from the coded material, which was kept on disk and protected by a password. Audiocassette tapes were kept in a locked cupboard. The transcriber of the tapes signed a confidentiality statement (Appendix 5). Transcripts were kept in a locked filing cabinet separate from the audio tapes. The researcher was responsible for the safe keeping of the texts. During the study, only the researcher, his transcribers and supervisors had access to all interview texts. The transcripts were submitted to be stored for five years minimum secure storage at Massey University. All participants were offered their audio tapes back after use, or the tapes were destroyed at their request. Participants were given the opportunity to view and correct all transcripts of the interviews, and were invited to read the thesis upon completion. All participants had the option to withdraw from the study during the interview phase and have their contribution destroyed (in their presence if they so wish). Throughout the analysis and write up, submitted material was kept anonymous (see below).

Anonymity and other issues

The parental interviews were entirely voluntary, anonymous and carefully monitored at every stage. Along with doctors and nurses, parents were reminded to avoid any identifiable features – such as names or places - of individuals or institutions during the interviews, and if they did so inadvertently, the researcher carefully edited material by substituting a code letter or similar. The reproduction of unsubstantiated opinion from any source concerning specific cases that could be interpreted as acrimonious towards any individual or group of individuals was actively avoided in the thesis.

Every effort has been made in this thesis to avoid potentially sexist language or gender typecasting. However, to avoid the unnecessary repetition of the ungainly ‘he/she’ or ‘she/he’, and also because four out of five of the nurses interviewed were female and all of the physicians male, the common convention of ‘she’ is used to denote a nurse, and ‘he’ for a doctor.²⁶ In the case of parents, there is less of a problem, and the correct pronoun is used.

Potential Harm to Participants

From the start of the study, it was realised that there was a potential risk of harm when delving into situations that may possibly disturb the emotional and psychological well being of the participant/s. This was particularly obvious in the case of any interviews with parents of young children who may have since died or remain seriously ill following the acceptance or refusal of medical treatment. After careful consideration of the notion of a more fieldwork/contextually based type of texts gathering, it was decided that specific observations of the interactions of parents and health care staff under considerable pressures and anxieties in the Paediatric Oncology area could be seen as both unnecessary and invasive. In light of the shift in the research proposal towards a broad exploration of discourses on the topic, and also when considering the need for further literature in the area, an interview based project was decided upon. With these problems in mind, the following actions were proposed to minimise the possible risks:

No parents were approached for interviews during the time of their stay within the hospital with their seriously ill child. All interviewees were given the opportunity to freely volunteer for the research through an entirely anonymous process. I was prepared to terminate an interview with any parent, nurse or doctor if, in my opinion, the participant was unacceptably distressed.

²⁶ Both words – ‘doctor’ or ‘physician’ are used interchangeably throughout this thesis to reflect not only common usage, but the mixed usage of the words by the interviewees as well.

Appropriate counselling services were to be offered to any of the interviewees if needed. These strategies were not required because no apparent distress was caused by the interviews.

Other risks

In regard to the possibility of the researcher gathering comments from health care personnel who have worked with the same child, it must be noted that this was not an intention of the study. In the interests of anonymity, no attempt was made by the researcher to establish whether or not the participant was talking about the same case as other participants. No material relating to an actual case was used in the thesis without the permission of the participant who provided the information. In the possibility of recognisable aspects of another individual being referred to by another participant, the general rule was one of caution when writing up the thesis.

The ultimate desire in doing this research was to seek ways to alleviate some of the pressures that fall upon parents and health professionals by exploring their roles in caring for seriously ill children - especially in those situations where there is a potential for disagreements and distress over a proposed medical treatment - so that a greater awareness and understanding of the issues may be developed. It was thought at the time that participation may serve to reassure nurses, doctors and parents involved in the care of seriously ill children that an active interest is being taken in the difficult problems that they have, and continue, to face. In general, there may be widely acknowledged benefits in the form of a wider debate about the problems encountered by parents and health care personnel when faced with difficult and sometimes controversial choices concerning the fate of children receiving medical care in New Zealand.

Analysis of texts

An outline of the desirability of the chosen analytical method for this study was provided by Cheek (2000) and Rolfe (2001) who provided initial ideas concerning the intellectual and intuitive "journey of exploration and discovery" (Cheek, 2000, p. 133) that was required to achieve the aims of this research. Fairclough's (1995) broad three-dimensional framework for studying discourse, "where the aim is to map three separate forms of analysis onto one another" (p.2) was also employed. This framework was a) analysis of (spoken or written) language texts, b) analysis of discourse practice (processes of text production, distribution and consumption) and c) analysis of discursive events as instances of sociocultural practice. This enabled the use of the written material employed in the thesis, and supported the notion of "language as a form of social practice" (Fairclough, 1989, p.20), that was emerging as a key element in the texts collected for the research. According to Parker (1992), "discourses do not simply describe the social world, but categorise it, they bring phenomena into sight... [they] provide frameworks for debating the value of one way of talking about reality over other ways" (pp. 4-5); Parker's four main stages of discourse analysis were used as a guide for the organisation and analysis of the research material. The four stages are:

Introduction: The study is positioned with respect to its relationship with other substantive works drawn from a 'traditional' search of literature. Other discursive studies may be included in this composition. Also, the types of texts to be analysed and the types of questions and issues that drive the research are discussed to supply a contextual basis for the research

Methodology: Detail is given about specific texts to be analysed, i.e. why these texts were chosen, why other texts were dismissed, and how these texts were obtained.

Analysis: Texts are examined using intuition, particular attention being paid to the absence of possible discursive frames and other emerging themes.

Discussion: The analyses are linked to other material in the area in order to draw out points for consideration of the substantive area under consideration. This stage involves reflection on the issues raised by the method, including the position of the researcher.

The works of Fairclough and Parker framed the analytical process; however a set of theories that would assist with analysis of the texts was needed. As the topic dealt largely with resistance, a decision was made to use selected Foucaultian methods and ideas, especially those relating to the uses of power, control and discipline. As material was collected for the thesis, it was decided to explore the *contextual* socio-political elements by using a selection of Bourdieu's main ideas about capital, habitus and field. A final layer of analysis and inspiration came from additional theoretical sources that offered context specific ideas for the substantive chapters in the thesis.

These additional sources were, in order of appearance in the thesis:

Chapter Four: Lupton (1994a, 1994b, 1995, 1999) and Lupton & McLean (1998), whose work in the field of media analysis and its relationship to medicine, illness and disease, helped to uncover 'latent' or 'sub textual' discourses.

Chapter Five: Stychin (1995), whose analysis of the discursive elements and resistance towards homosexuality in law lent itself well to a similar analysis and deconstruction of the law's position regarding radically resisting parents.

Chapter Six: Young, Dixon-Woods and Heney (2002), and Young, Dixon-Woods, Findlay and Heney (2002a), and to a lesser extent of Dixon-Woods, Young and Heney (2003; 2005) provided works on cultural discourses relating to children, parenting, caring, and cancer or chronic illness. Their ideas assisted with the analytical framing of the texts concerning parents' responses to medical interventions on their children.

Chapter Seven: Lupton's (1994a; 1996; 1997) work on the cultural aspects of medicine provided theoretical framing for an analysis of the texts gathered from doctors interviewed for the research.

Chapter Eight: Bishop and Scudder (1990, 1991, 1996), whose ideas on nursing's 'in-betweenness' were used in an analysis of the interviewed nurses' responses to parental resistance.

All were used in conjunction with the selected ideas of Foucault and Bourdieu, which informed every chapter.

When examining texts, the process was mainly one of intuition and theoretical application, where the main analytical structures were selected from a variety of sources supported by key ideas taken from Foucault and Bourdieu. As an analogy, the analysis was supported with key Foucaultian and Bourdieusian ideas providing a type of philosophical and sociological 'weave and weft' effect, the chosen additional contributors providing the discursive 'pattern of the fabric', and the interviews and other texts providing the raw material for the 'fabric.' Finally, the process was completed after a great deal of constructing, deconstructing and reconstructing (rewriting) of the discursive material.

Consistency and credibility issues

The thesis employs philosophical ideas and approaches to research that are supported by the works of Foucault, Bourdieu and other significant contributors from a mainly post-structuralist pool. It therefore does not necessarily purport to claim "any aspect of reality in its entirety, speak for others, make truth claims, and attain universal essential understandings" (Cheek, 1999, p. 384). On the contrary, it seeks only to present, through an examination of several different and often conflicting 'texts', a multiple and varied cultural representation of parents who resist medical treatment for their child that pays attention to multiple realities and interpretations of discourses and practices within the field. In such a qualitative thesis, the credibility of the results depends largely on consistency with established literature and themes across the interviews, and the experiences of the researcher as a nurse and an expert in the field (Thurmond, 2001).

To ascertain whether or not such consistency has been achieved, central ideas and themes of the thesis have been presented to different gatherings of parents, doctors, nurses and academics (Woods, 2002, 2003, 2005, 2006a, 2006b) in the last few years; on each occasion, these ideas and themes have been accepted by those groups as being a credible account of the topic. According to Cheek (2000), reflexivity brings into scrutiny not only the research field itself, but also to how the field is represented by the researcher in the research text. The researcher chooses, positions and constructs the field, while the field simultaneously positions and constructs the researcher. According to Jacobson & Jacques (1997), the use of such a perspective is an attempt to "become more reflexive about the ways that situated knowers and knowns influence the production of inevitably perspective-dependent knowledge" (p.56). This thesis is therefore a constructed account that brings together the stories of the research participants with media, legal and academic texts about parents who resist proposed medical treatment for their seriously ill children.

Summary

This chapter has considered the philosophical background to the chosen methodology and method for this thesis on parental resistance. It has been shown that this background has emerged from poststructuralist thinking in the second half of the twentieth century, and in particular from the ideas of both Foucault and Bourdieu. It has also been shown why in this thesis selected main ideas from both of these particular social theorists have been utilised. Furthermore, it has also been maintained that it is the combined strengths of the analytical ideas of both theorists that strengthens and supports the thesis, including the strength that is obtainable from merging the approaches to research of both.

The chapter also discussed issues relating to methodology and method to illustrate the processes undertaken to provide a poststructuralist thesis that is both robust and flexible. In particular, it has been shown that the methods used to realise the research aim were the result of a gradual and sometimes serendipitous process. A detailed and thorough examination of the ever emerging issues involved in performing the research for the study has also been offered. It is maintained that from the overview of the design of the study, to its procedures, to the method of analysis, there is a very carefully considered methodological underpinning for this thesis that is both consistent and reliable.

CHAPTER THREE

Consent, decision making, the law and parental resistance

I think there's greater sensitivity, but in my view the courts will always intervene in all the [difficult] treatment cases. If the doctor says it's got a 50% or better prognosis and they're talking about serious harm or death, they will intervene - that's my view (Health & Disability Commissioner, personal communication, September 3, 2002).

Introduction

This chapter offers a critical review of literature concerning consent and the relationship between children, their parents, medicine and the law in matters of health related decision making. Arguments presented in this chapter provide a 'backdrop' to future discussion (see Chapters Five and Seven) concerning the use of legal and medical means to sanction desirable parental behaviours and to prohibit those deemed undesirable. In this chapter the role of the law in cases of parental resistance, where it will be argued the law acts as a surrogate force for medicine in a set of 'gentlemen's rules' between medical decision making and the enforcement of law, will be highlighted. It is argued that cases involving resisting parents bring to focus tensions between the perceived rights of individuals (parents and their children) and the degree of control allocated to medical and legal professionals who act as representatives of the state.

The chapter begins with an exploration of textual representations of the concept of choice and consent in health care settings, and in law as it relates to children and their parents. In New Zealand, the law relating to informed choice and subsequent care within the medical field has changed significantly in recent years. This legislation is briefly described and an examination of texts concerned with explanations of parental refusal of consent in the health care setting considered. The chapter continues with a review of texts associated with decision making in health care settings, offering a critique of the ways in which medical and parental decisions are represented in the literature. In this section, emphasis is given to the following concepts: an individual's 'capacity to choose' which is used extensively in legal texts; 'best interests', which is used in both medical and legal texts to signify the aim of decision making in health care, and 'parental autonomy', a much promoted ideal in medical and legal texts that is often challenged in practice.

To assist in the discussion of the texts used in this chapter, analytical ideas from Austrin and Phibbs (1996) and Irwin and Jordan (1987) are considered. Austrin and Phibbs provide a Foucaultian analysis of how registers are used to facilitate informed consent and to regulate screening practices for cervical screening and silicone breast implants. Their exploration of issues surrounding consent, trust choice and control in the problematisation of registers is extended to assist in the analytical framing of legislation surrounding parental resistance. There are similarities between the use of national registers in response to issues of consent, trust and

choice and the use of legislation in response to problems associated with parental consent in this thesis. It is argued that the legislation has a dual purpose of facilitating choice and informed consent, and of regulating relationships between children, parents and physicians. Irwin and Jordan's analysis of the use of medical 'knowledge, practice and power' within court ordered caesarean sections highlights how the individual effects of medical knowledge and decision making are related to complex social processes. When they examined a number of legal cases, Irwin and Jordan found that individual challenges to medical authority may be overruled by legal orders supporting the practice of medicine further legitimating medical knowledge. When medical decisions are challenged or rejected, their analysis suggests that birthing becomes 'an arena of struggle' where the hegemonic relationship between physician and woman (which is transposed as being between doctor and parent in this chapter) becomes visible.

The main arguments in this chapter are concentrated around the conceptual representations of consent and decision making within health care institutions, and on the issues that arise when parental consent is not given for medical treatment. It is argued that the literary representations of choice and consent in decision making are based around neo-liberal notions of choice as an individual rather than collective property. The construction of choice as an individual property within the medical literature is contrasted with legislation surrounding consent which indicates that choice is also a collective property that is overseen by the state. One of the sites in which this tension between the individualised and collective properties of choice is worked out is in legal cases involving parents who refuse medical treatment for their children. In addition, choices are offered within a health system that forces parents to make decisions that are either limited in range or thrust upon them by circumstances. It is maintained that some choices are culturally sanctioned, being afforded medical and/or public approval, others not; it is the unauthorised choices which bring into play the full legal and medical apparatus of the state. In such cases it is argued that ideas about individual choice in health care, especially where parents act as surrogate decision makers for an individual child, is illusory; and that it is the state, through the mechanisms of both medicine and law, that forces a decision through appeals to the collective needs of society at large.

Choice and consent in health care

The modern notion of informed consent can be traced back to the experimental atrocities that occurred under the Nazi regime in Germany and many other countries during the 1930s and 40s. Most of the atrocities perpetrated by Nazi scientists were done so in the name of scientific research and under a professional ethos that held that the patients' interests were best served by trusting doctors (Caplan, 1989). After the war, the war crimes tribunal produced a written code thereafter called the 'Nuremberg Code' (Proctor, 1992) which began with the now famous statement: "The voluntary consent of the human subject is absolutely essential." Later, other

codes, such as the Declaration of Helsinki 1964, outlined the main ethical components of informed consent. In recent times, an international set of guidelines has been produced to reassert the primacy of informed consent (Council for International Organizations of Medical Sciences, 1993). In this code, and in previous examples, the underlying principle of informed consent is that a physician has a duty to disclose to a patient information to allow the patient to make a reasonable decision regarding his or her own treatment.

New Zealand legislation – informed consent

In New Zealand, an individual's right to accept medical treatment or refuse it (even if death will occur because of his/her actions) is a now widely accepted norm that is embedded within ongoing systems of social relationships (Lowe, 1997). Its origins are traceable back to the Nuremberg Code, and it is well represented in legislation such as the Human Rights Act of 1990 (Section 11), and through later via the Code of Health and Disabilities Services Consumers Rights (1996, hereafter called 'the Code'), which applies to children when and where appropriate. This is because following New Zealand's ratification of the United Nations Convention on the Rights of the Child in 1993, the law relating to treatment decisions for children became the same law as for adults. That is, the law sees children as individuals in the same way as it sees adults. Within the Code, there is no 'age of consent' and *all* consumers of health or disability care are constructed as competent to make an informed choice and give consent, or otherwise, for treatment. The Code expects all health professionals to treat each child as competent to decide unless there is good reason to suppose otherwise.

In the case of young children, the Code provides for an assessment of competency in relation to *a particular service*. As such, it is generally accepted that a child of six or seven will be asked if they will allow a doctor to examine him/her, but it is a quite different scenario when a young child is expected to decide whether or not they wish to undergo treatment by chemotherapy. In such situations, the rule of competency generally gives way to a more parentally focused decision, the argument being that children under ten or twelve are not usually expected to be capable of making such a decision alone, or even at all. In the Code, which is legally enforceable, a mentally competent 'consumer' of health care, who is fully understanding of the consequences of refusing life-preserving treatment, has the right to refuse any proposed treatment of any kind. Yet, if the 'consumer' of health care is deemed less than fully mentally competent, i.e. to have "diminished competence," then (according to the level of competence) an appropriate amount of individual choice is still acknowledged under the Code. If the 'consumer' is not competent to make an informed choice, then it is expected that another person, who is entitled to consent on behalf of the consumer, will be allowed to consent on their behalf. This process is regarded as the norm in most cases in the consent for medical treatment of those who are younger than the legal age of consent, which is 16 years.

For Foucault (1983, p. 144), judicial codes and legislative activity make “an essentially normalising power acceptable.” The New Zealand Code was set up in response to a scandal involving unethical conduct in the provision of medical services at National Women’s Hospital in Auckland. The Report of the Cervical Cancer (Cartwright) Inquiry (1988) involved a judicial investigation into the unethical and experimental treatment of women for carcinoma in situ, in which the medical profession was represented as betraying trust by withholding information about the ‘trial’ and the implications of medical interventions (or in many cases, non-interventions) for the women involved. Betrayal of trust is generally seen as a private trouble between a physician and his patient. However, when betrayal of trust becomes a public issue, as in the Cartwright Inquiry, collective problems of trust have to be (re)negotiated (Austrin & Phibbs, 1996). In both the Nuremberg Code and the New Zealand Code, a discourse of rights is linked to legislation which is designed to empower people in their relationships with the medical profession (Austrin & Phibbs, 1996). Within the legislation, the problem of trust is reinterpreted as a problem of individual rights regarding choice and informed consent. Thus, informed consent and individual rights are constructed as a solution to issues of trust in the provision of medical services. The construction of choice and informed consent as an individual property, rather than a collective property, is clearly illustrated within the medical literature and in standards for professional practice as outlined below.

The concept of informed consent in medical practice and law

Discourses governing biomedicine and biotechnology within neo-liberalist nations often revolve around issues of choice, consent, ethics and responsibility (Campbell, Charlesworth, Gillett, & Jones, 1997; Culver, & Gert, 1982; General Medical Council, 1998). Obtaining consent for medical treatment or research is seen as both an essential legal and moral right in many western countries. According to Faden and Beauchamp (1986), there are two distinct meanings, or senses, of informed consent, namely autonomous and/or effective. Autonomous informed consent is a term used in the moral sense, and is described by Faden and Beauchamp as “autonomous authorization”. That is “an autonomous action by a subject or patient that authorizes a professional either to involve the subject in research or to initiate a medical plan for the patient” (1986, p. 276). This meaning of informed consent implies substantial understanding, absence of control by others, intention and authorisation. Effective informed consent is a socio-legal concept, and is defined by Faden and Beauchamp as “a legally or institutionally *effective* (sometimes misleadingly called *valid*) authorisation from a patient or subject” (1986, p. 281). In this regard, the informed consent obtained needs to satisfy not only institutional policies, procedures, and cultural and professional practices, but legal standards as well.

By common definition, informed consent involves obtaining "...a patient's written consent to a surgical or medical procedure or other course of treatment, given after the physician has told the patient all of the potential benefits, risks, and alternatives involved..." ("Informed consent", 2001). Yet this rather basic understanding was once not well defined, and it was not until legal decisions in relation to cases involving informed consent were applied to statutory laws that more strict and binding definitions finally came into being.²⁷ However, it may still be argued that the development of standardised and comprehensive policies on informed consent owe their existence to the neo-liberalist developments of the late as the 1970s and 80s, a time when finally there was much more concerted focus on individual rights and responsibilities in health care at the consumer level. In recent years, at least three legal standards of informed consent have emerged from literature and been applied to modern health care settings in several countries, including New Zealand. These standards are conceptualised as follows:

The professional practice standard

This standard is set by the custom and practice of physicians in the medical community:

Informed consent...is the name for *a general principle of law* that a physician has a duty to disclose what a reasonably prudent physician in the medical community in the exercise of reasonable care would disclose to his patient as to whatever grave risks of injury may be incurred from a proposed course of treatment so that a patient, exercising ordinary care for his own welfare and faced with *a choice* of undergoing the proposed treatment, or alternative treatment, or none at all, can, in reaching a decision, intelligently exercise his judgment by reasonably balancing the probable risks against the probable benefits....(ZeBarth v. Swedish Hospital 1972, italics added).

As a 'general principle of law', this standard acknowledges the collective regulation of consent whilst at the same time suggesting that individual choice in individualised contexts is of paramount importance. It is therefore an example of the construction of informed consent as an individual property within a collective framework.

The reasonable person standard

This is a standard set by considering what a reasonable person in the patient's position would want to know in order to make a decision:

The test for determining whether a particular peril must be divulged is its materiality to the patient's decision.... A risk is thus material when *a reasonable person*, in what the physician knows

²⁷ For instance, an early case, which had a profound effect on American law for several years, was heard by Justice Cardozo in 1914. Hearing a case where a person had been operated upon without consent, he concluded that: "Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault for which he is liable in damages" (*Schloendorff v Society of New York Hospital*, 105 N.E. 92 (N.Y., 1914).

to be the patient's position, would be likely to attach significance to the risk or cluster of risks in deciding whether or not to forgo the proposed therapy (*Canterbury v. Spence*, 1972; italics added).

The key concept in this standard is clearly 'reasonable person', which is based upon the (subjective) judgements of the physician; it is therefore virtually impossible to define. In practice, the notion of a reasonable person as related above may therefore vary according to the physician's interpretation of the patient's position, which in effect, may only be a hypothetically decided 'reasonable position' based on little more than a set of medically orientated presumptions.

The subjective standard

This standard is based upon the notion that a patient should be informed of everything that all *rational persons* would want to know; i.e. each patient would want to know of every reasonable medical alternative that might affect his or her personal decision. This decision itself might rest upon religious or cultural beliefs, or even superstitions that would influence which alternative they would choose (Culver & Gert, 1982). This standard is also thought to apply to the disclosure of potential risks and benefits including mortality and morbidity rates for a proposed procedure in a hospital or a medical centre by their physician. There are clear legal overtones of compensation.

In all three of the legal standards there are a number of premises that are based on a particular 'body politic'²⁸ that is embedded in a 'general principle of law', as are notions of 'a reasonable person', and 'rational persons', which are based on modernist arguments about logical and judicious decision making. Subsequently, in the *Code of Health and Disability Services Consumers' Rights, 1996* (Right 7:7), it is a mentally competent 'consumer' of health care, who has the right to refuse any proposed treatment. Yet, if the 'consumer' of health care is deemed to have "diminished competence," then a limited amount of individual choice is still acknowledged under the Code. If the 'consumer' is not competent to make an informed choice, then another person will be allowed to consent on their behalf.²⁹

Where individual choice is transferred to parents because of the child's age, a refusal may still be met by legal action because doctors are in command of resources and are therefore at an

²⁸ I.e. that there are correspondences between society or the state and the individual human body. In the simplest form, the body politic asserts that given the organic nature of the state (where a "natural" society is one which functions in a manner similar to the human body), then certain political structures or actions are necessarily appropriate.

²⁹ It is quite possible for medical practitioners to be confronted by a patient or the parent of a child patient who for all intents and purposes is rational, but refuses a course of action in a fashion deemed by the physician to be questionable or irrational. Generally speaking, the capacity to make treatment decisions, including withholding or withdrawing treatment, is considered intact if the patient understands the clinical information presented, appreciates his/her situation, and is able to display reason in deliberating about their choices. If they are not, then their choice is seen as grounds for pursuing legal actions to secure the right to treat that person whether they comply or not.

advantage (Irwin & Jordan, 1987). Doctors as agents of the state make judgements about the competency of individuals to make decisions about their health care and the rationality of their decisions. The construction of the rational individual as someone who makes decisions that will maximise their self interests reflects neo-liberal economic thinking that tends to separate economics from social relations, thereby promoting an 'under-socialised account' of action that 'atomises' human behaviour even if, as Granovetter (1985) argues:

Actors do not behave or decide as atoms outside a social context, nor do they adhere slavishly to a script written for them by the particular intersection of social categories that they happen to occupy. Their attempts at purposive action are instead embedded in concrete, ongoing systems of social relations (p.487).

The resultant schism between a context of neo-liberalist individualism, the state sanctioned acts of a physician, and the socially embedded and relational individual may therefore be a profound one under certain circumstances, such as those surrounding the obtaining of informed consent from parents on behalf of their children.

The legal concept of informed consent in regard to children and their parents

As may be seen from the previous discussion, there is considerable debate over whether special populations, such as children and the mentally ill, can ever really be considered to have given fully informed consent. This is because even though there is little dispute concerning the rights of individuals over the age of sixteen years, the presumed age of individual and social responsibility, there remains a large 'grey area' involving the rights of children under this age.³⁰ Indeed, there is a continuous tension between the rights of children and the rights of parents to choose on their behalf (Taylor & Pinnock, 2001). This tension is the product of a growing development in children's rights from the highest international levels (such as the United Nations Convention on the Rights of the Child, 1993) to the maximum national levels. In the case of New Zealand legislation, there has been a dramatic shift away from parental control towards much more extensive child control. For most of the nineteenth and twentieth centuries, parents, especially fathers, were legally responsible for their children's welfare, and made all decisions for their children in nearly all settings, including health care settings. This duty was recognised in common law (Fletcher & Hussey, 1999). This situation has been adjusted in recent years by changes to legislation concerning the rights of children to choose for themselves. Such rights have been reflected in several western nations, including New Zealand

³⁰ This is largely because of differences in views concerning the constructions of childhood. According to Jenkins (1993), there are four, namely children as possessions, subjects, participants and citizens, each of which affecting the viewpoint that children have rights. New Zealand law tends to promote children as citizens who have similar rights to adults.

(see next section), England and Wales (Children Act, 1989), the United States (various State laws reflecting a 'mature minors' approach³¹) and Australia (e.g. in Victoria, the Children and Young Persons Act, 1989).

The promotion of greater autonomy for patients in the health care system has given rise to greater challenges for the providers of care as some of the issues surrounding the rights of children and/or their parents to accept or refuse medical treatment have become clouded in recent years. During this time, the introduction of legislation has brought legal and ethical pressure to bear upon doctors and nurses to more closely involve *all* patients, young and old (or their legal guardians) when making important decisions regarding their proposed treatment or care. Such decisions are not always easily or lightly made, especially if and when those decisions are 'life and death' decisions involving children; nor are these decisions always ones that all parties, the parents of the children in particular, may agree upon. As such, consent procedures remain problematic in these instances, and, as Austrin and Phibbs (1996) note, contribute to an ambiguity of consent and trust that is clouded by issues that link "information and understanding about the potential risks involved in a medical procedure to freedom of choice" (p.18). These is because many treatment decisions involve a significant degree of risk, discomfort and stress for child patients and their families, and yet are delivered within circumstances where consent is constructed as an individualised property negotiated between a physician and a patient. Parents and surrogates problematise this ideal, necessitating specific legislation and alternative ways of negotiating consent. This binary opposition between the individualised and relational contexts of decision making does not lend itself easily to critical decision making, especially in an age where the instances of decision making involving complex ethical deliberations is increasing rather than decreasing, largely due to rapid advances in modern medicine, science and technology (Beauchamp & Childress, 1994).

A number of Acts have been enacted in New Zealand in the last few decades that illustrate the tension between individual and collective rights relate to the rights and responsibilities of children and their care givers, which includes doctors, nurses and parents/guardians who care for children in those situations concerning medical treatment in New Zealand. A brief overview of those Acts that are related to these rights and responsibilities now follows:

³¹ For a comprehensive explanation of the diversity in United States mature minor laws, see Boonstra & Nash, 2000).

The Crimes Act 1961

This Act consolidates and amends the Crimes Act, 1908 and certain other enactments of the Parliament of New Zealand relating to crimes and other offences. The Act is vast covering several broad areas of criminal activities and their legal ramifications, but two sections relating to the necessities of life and parental responsibility are particularly pertinent to any discussion concerning the medical treatment of all persons, children included, in New Zealand.

Section 151 of the Crimes Act is concerned with meeting 'the necessities of life' for those who are dependent on the care of another person:

Section 151

(1) Every one who has charge of any other person unable, by reason of detention, age, sickness, insanity, or any other cause, to withdraw himself from such charge, and unable to provide himself with the necessities of life, is (whether such charge is undertaken by him under any contract or is imposed upon him by law or by reason of his unlawful act or otherwise howsoever) under a legal duty to supply that person with the necessities of life, and is criminally responsible for omitting without lawful excuse to perform such duty if the death of that person is caused, or if his life is endangered or his health permanently injured, by such omission.

2) Every one is liable to imprisonment for a term not exceeding 7 years who, without lawful excuse, neglects the duty specified in this section so that the life of the person under his charge is endangered or his health permanently injured by such neglect.

Section 152 of the Crimes Act is specifically orientated towards parental responsibilities to provide the necessities of life:

Section 152: Duties of parents to provide the necessities of life

1) Every one who as a parent or person in place of a parent is under a legal duty to provide necessities for any child under the age of 16 years, being a child in his actual custody, is criminally responsible for omitting without lawful excuse to do so, whether the child is helpless or not, if the death of the child is caused, or if his life is endangered or his health permanently injured, by such omission.

2) Every one is liable to imprisonment for a term not exceeding 7 years who, without lawful excuse, neglects the duty specified in this section so that the life of the child is endangered or his health permanently injured by such neglect.

It is this Section which is relied upon in courts of law to prosecute parents who have been charged with neglect or abuse of their children, or in some cases, with parental refusal to accept the medical advice offered by physicians in response to a serious childhood illness (as occurred, for instance, in *Healthcare Otago Ltd v Williams-Holloway* [1999] NZFLR 804 & 812; *R v Laufau* [2000] T000759; and the *Tribble* case ("Tribble Baby Death Not Manslaughter", 2005).

Children, Young Persons and their Families Act 1989

This Act relates to children and young persons who are in need of care or protection or who offend against the law and, in particular:

(a) To advance the well-being of families and the well-being of children and young persons as members of families, whanau, hapu, iwi, and family groups:³²

(b) To make provision for families, whanau, hapu, iwi, and family groups to receive assistance in caring for their children and young persons:

(c) To make provision for matters relating to children and young persons who are in need of care or protection or who have offended against the law to be resolved, wherever possible, by their own family, whanau, hapu, iwi, or family group:

(d) To make provision for the appointment of a Commissioner for Children:

In regard to medical care in particular, a child or young person is in need of care or protection within the meaning of the Act if:

(a) The child or young person is being, or is likely to be, harmed (whether physically or emotionally or sexually), ill-treated, abused, or seriously deprived; or

(b) The child's or young person's development or physical or mental or emotional well-being is being, or is likely to be, impaired or neglected, and that impairment or neglect is, or is likely to be, serious and avoidable; or

(c) Serious differences exist between the child or young person and the parents or guardians or other persons having the care of the child or young person to such an extent that the physical or mental or emotional well-being of the child or young person is being seriously impaired.

The Care of Children Act 2004

This Act was introduced into New Zealand law to repeal the Guardianship Act³³ of 1968 and to strengthen the protection of children in society through a new set of rules for appointing guardians. This lengthy Act 'opens up' access to Family Court hearings (i.e. specific legal courts involving children and their families) and provides for stronger representation for children within the legal system. The purpose of the Act is described as a) to promote children's

³² 'Whanau' indicates the extended family; 'hapu' – sub-tribe or kinship group that is linked to a common ancestor; 'Iwi' – tribe, or indigenous nation state.

³³ This Act was instigated to define and regulate the authority of parents as guardians of their children, their power to appoint guardians, and the powers of the Courts in relation to the custody and guardianship of children. The Act supported the child's right to what is considered as appropriate care, including health care, by arranging to have the child taken into care (i.e. into a guardianship arrangement) if it is deemed in 'the best interests' of the child. This Act allowed for those situations where not only the child's welfare is threatened by continued presence with his/her parents, but where the child's health is thought to be at risk in cases where parents refuse certain medical interventions (such as may occur in cases of Jehovah's Witness children and blood transfusions).

welfare and best interests, and facilitate their development, by helping to ensure that appropriate arrangements are in place for their guardianship and care; and b) to recognise 'certain rights' of children. To this end, the Act defines and regulates:

(i) Parents' duties, powers, rights, and responsibilities as guardians of their children:

(ii) Parents' powers to appoint guardians:

(iii) Courts' powers in relation to the guardianship and care of children:

It also acknowledges the role that other family members may have in the care of children; respects children's views and, in certain cases, recognises their consents (or refusals to consent) to medical procedures; encourages agreed arrangements for, and provides for the resolution of disputes about, the care of children; makes provision for enforcing orders internationally; implements in New Zealand law the Hague Convention on the Civil Aspects of International Child Abduction and finally it reforms and replaces the Guardianship Act 1968 (including the Guardianship Amendment Act 1991).

For Bourdieu, a 'field' is a set of networks, meanings, rules and institutions through which identities are constituted and social practices legitimated (Bourdieu & Wacquant, 1992). The limits and boundaries of the field are marked by institutional exclusions that are defined by the field itself. The legislative Codes and Acts outlined above, for example, draw attention to the norms by which social convention involving professional practice, informed consent and parental responsibility are authorised, institutionalised and regulated. Practices that are intelligible within the legislative field (standards for professional practice, a reasonable person, rational decision making, parental responsibility, legal conduct) are juxtaposed against those that are not (subjective judgements about unreasonableness, understandings about professional practice, irrational decision making, irresponsible parents or criminal conduct) drawing attention to where the limits of each of the relational fields (parents, children, physicians and parents) to which the legislation refers are located. These exclusions, which mark the boundaries of the fields in which they are embedded, are always contestable – as places of struggle they are also potential sites for disruption and change:

As a political compromise between irreconcilable demands, presented as the logical synthesis of antagonistic theses, a judgment contains within itself the whole ambiguity of the juridical field. It owes its effectiveness to its simultaneous participation in the logic of two separate fields: the political, characterized by the opposition between friends (or allies) and their enemies, in which the tendency is to exclude the intervention of any third person as arbiter; and the scientific, which tends to grant practical primacy to the opposition between truth and error, granting effective decision-making power to an agreement among specialists (Bourdieu, 1987b, pp.830-831).

Resisting parents trouble understandings about parental responsibility, reasonableness and rational decision making, bringing together each of these legislative fields in a contest over the meanings associated with actions that are unauthorised within the dominant legislative discourses. Medicine and law shore up the legislation by ensuring that acts that are not

sanctioned by the state remain illegitimate and punishable by law. However, it is precisely because standards are subject to variability and contestation (Phibbs, 2000) that they are formalised within the legislative apparatus of the state. It is therefore possible to see resisting parents not as peripheral to the physician/patient encounter but as examples of how relationships between individuals and physicians come to be institutionalised and regulated through the administrative apparatus of the state.

Parental refusal of consent in health care settings

Overall, the promotion of greater autonomy for patients in the health care system through legislative means has given rise to greater challenges for the providers of care, and some of the issues surrounding the rights of children and/or their parents to accept or refuse medical treatment have become problematic in recent years. In most instances the treatment regime that is offered by a physician in response to a serious childhood illness such as cancer is alarming and distressing for the child and her/his parents (Comaroff & Maguire, 1981; Eisenberg, Kessler, van Rompay, Kaptchuk, Wilkey, Appel et al. 2001; Yeh, Lin, Tsai, Lai & Ku (1999); Young, Dixon-Woods, Findlay and Heney, 2002; Young, Dixon-Woods & Heney, 2002).³⁴ When medical interventions are lengthy, involve hospitalisation, and the administration of powerful drugs with considerable side effects, the degree of possible ill-ease must increase. Chemotherapy and/or radiation therapy is often costly in terms of side effects. In cases involving a child, the child may lose hair, suffer nausea and vomiting, malaise and fatigue, mouth ulcers and risk severe infections through lowered immunity levels (James, Ashwill, & Droske, 2002).

Despite the challenges outlined above, most parents accept the difficulties of prolonged and complex medical treatment if it is thought to be in the best interests of the child, and recovery is at least a possibility, however small the odds. This is thought to be because a future orientated temporal domain takes precedence, i.e. the possibility of an eventual cure takes priority over the immediate distress of the treatment (Lawler, 1991). Nevertheless, in some critical situations involving children and their parents, such treatment proposals may cause several problems for both parents and health care staff alike. Parents, for example, may be asked to make treatment decisions on behalf of their child but at the same time it is expected under the Code of Health and Disabilities Services Consumers Rights, 1996, that the child still be allowed to consent to certain procedures as far as competency allows. There are also a number of cases of parents

³⁴ Cancer per se is uncommon in children yet it is the second leading cause of death after accidents in the USA, for instance, where fourteen childhood cancers occur per 100,000 children under the age of 15 years (Greenlee, Murray, Bolden, & Wingo, 2000).

who either chose to resist medical advice and treatment for their child at the start of the medical consultation, or later, after initial treatment had commenced (Ansley, 1999; Carter, Stickley, Inglis & Laxton, 2002). Parents may turn to 'complementary and alternative medicine' (CAM) which represent "a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine" ("What is complementary and alternative medicine?" 2003; see also Appendix 7). Such non-traditional or non-scientifically based medicines have nearly always regarded been with deep suspicion by the medical profession (Ernst, 2001; Ernst, Resch & White, 1995) although through a rapidly growing public use of CAM therapies, doctors are gradually responding in a more balanced fashion (Owen, Lewith & Stephens, 2001).

Representations of the causes of parental resistance in literature

Parental resistance to medical treatment is a socially located discourse that seeks ways to explain undesirable actions in relation to causes and symptoms. Medicine identifies the signs of, and reasons for, parental resistance through observations and record keeping. Over time, this knowledge accumulates providing an 'evidence base' that allows physicians to associate certain characteristics (such as religious beliefs or cultural background) with a particular type of (potentially resistant) individual (Foucault, 1975). This process of record keeping is what Foucault referred to as a 'modern technology of power' (Foucault, 1977) which enables "a constructed medical gaze is able to penetrate and organise the population" (Austrin & Phibbs, 1996, p.17). The drawing up of lists that identify signs of parental resistance, and the documentation and interpretation of cases within medical, academic or research based literature are part of the process whereby resistance is constituted in scientific terms (Foucault, 1982). The most commonly seen causes of parental resistance to medical treatment in literature include religious grounds, preferences for less invasive treatments, distrust of the health care system, doctors and/or drug companies, differing socio-cultural belief systems, psychological factors and ignorance, neglect or abuse. Each of these causes is now briefly examined.

On religious grounds

It has been suggested that in a small but significant number of the cases, perhaps especially so in those cases involving children belonging to particular religious groups within society, that some parents do not easily accept the requirements of conventional medicine (Brody & Engelhardt, 1987) These parents, when refusing conventional treatment, offered strong religious reasons such as the belief that the child's illness was an illusion because of lack of faith; or

certain treatments are forbidden in the Bible; or through revelation, the power of prayer alone will save the child (Orr & Genesen, 1997).³⁵ Nevertheless, although members of minority religious groups have different values and belief system from the 'mainstream', it does not necessarily follow that the parents of seriously ill children who belong to such groups will reject medical assistance in its entirety. As Brody and Engelhardt (1987) maintain, there are at least three main variations of parental response where religious objections to treatment are concerned. They are:

a) Parents who regularly refuse on religious grounds all forms of standard health care for their minor children (as is frequently the case for Christian Scientist parents).

b) Parents who regularly refuse on religious grounds certain specific forms of standard care for their minor children whilst at the same time accepting other forms of care (as is often the case with Jehovah Witness parents).

c) Parents who regularly accept standard care for their minor children but who on special occasions reject a major proportion of standard care (as is thought to be the case with Pentecostal parents).

A preference for less invasive treatment

In other cases of parental resistance, and especially those cases where the child faces months of invasive, systematically taxing or psychologically disturbing treatments, some parents believe that medical treatment is no better, or even considerably worse for the child, than alternative and less invasive treatments, which they prefer. The stated reasons for such alternative choices often include fear of the harmful effects of surgery and drugs, diagnostic and treatment errors in conventional medicine, the failure of conventional medicine to offer a guarantee of success, the notion of 'natural' equating to 'better and safer', the expense of conventional medicine, ignorance of the value of conventional medicine, magical/miracle overtones in alternative medicine, and a belief that the alternative medicine works as well as conventional medicine (Cant & Sharma, 1996; Eisenberg et al., 2001). In conjunction with this trend, there has been a noticeable and sustained rise in the emergence of 'healthy lifestyle without drugs' literature in hardcopy and electronic formats. This literature tends to promote natural responses to health maintenance and disease prevention such as a positive mental attitude, detoxification and a

³⁵ Often noted are those belonging to Christian Scientist and other minority faiths (Massachusetts Citizens for Children, 1992). According to J.G. Melton, Director of the Institute for the Study of American Religion, "since the 1960s there have been increasing numbers of members of other denominations who have been charged with crimes for turning to prayer rather than medicine for their kids" ("faith healing", 2003).

healthy diet in preference to a dependency on formal medicine, medical technology and 'unnatural' pharmaceutical products (Murray & Pizzorno, 1998). For some parents, the lure of using only natural products as 'cures' for normally highly dangerous disease states such as various forms of childhood cancer must therefore be a powerful one (see for instance, "Cure or prevent cancer naturally", 2003).

Distrust of the health care system/physicians/drug companies

Modern trends in health care suggest that the general populace as a whole, and certainly some cultural groups within the general populace, is turning more towards self help and traditional medicines, and less towards conventional medicine for at least minor health ailments, and in some cases, major ones such as cancer as well (Aoki, 1998). This gradual movement is thought to be related to the emergence of notions such as modern medicine and physicians are putting disease and research first and people second, 'organised medicine' being less trustworthy, and medical representatives being in cahoots with drug companies to make huge profits by taking risks with the use of certain substances such as vaccines and new, but improperly researched medicines (Eisen, 1999; Kirby, 2005).

The trend towards self help and suspicions of medical complicity in economic profit before lives has been greatly assisted in recent years by the huge uptake of self-help health sites on the Internet which can range from the largely traditionalist and conservative (such as the BBC's medically led health site simply called 'Health', 2006) to the antiestablishment, liberalist and sometimes 'fundamentalist' sites (such as 'NewsTarget.com' which frequently features attention grabbing headlines such as "State-sponsored medical terrorism: Texas authorities arrest parents, kidnap their teenage daughter, and force her through chemotherapy against her will" [Black, 2006] or "If prescription drugs are so good, where are all the healthy drug takers?" [Adams, 2004]).

Different socio-cultural beliefs and values

It is sometimes argued that differences in life philosophy, life values (i.e. fatalism vs. existentialism), and interpretation of 'the facts', the meaning of the illness, how the illness must be dealt with, and the degree of trust in modern medicine versus faith in traditional healing practices may all contribute to the different responses of different cultural groups within society (Spector, 2003). For instance, in some South East Asian cultures, surgery is considered to result in perpetual imbalance, causing the person to be physically incomplete in the next incarnation (Fadiman, 1997), and in New Zealand (which comprise 15% Maori and 7% Pacific Island of the total New Zealand population [Statistics New Zealand, 1999]), traditional healers and their treatments are often as respected as conventional doctors and their methods (Jameson, 1997).

In a country with a population as small as New Zealand's, there are several distinct ethnic groups that exhibit a wide range of cultural differences, and there are a number of groups

representing other perspectives as well.³⁶ For instance, the cultural acceptance or rejection of aspects of western medicine may be based on ethnic values, or on gender preferences and partnerships, or on religious affiliations (Macdonald, 1999). As a brief example, traditional Chinese medicine has a very long history of use amongst the Chinese community in New Zealand. It includes the use of acupuncture, herbs, tuina (medical massage) and qi gong (medical breathing) (New Zealand School of Acupuncture and Traditional Medicine, 2006). Such practices are often seen as being both less invasive and as effective as western medicine by those who use them, and it is therefore more likely that these cultural groups would seek to use such medicines when faced with serious illness as well as more common ailments. There is a high likelihood therefore, that some parents within certain socio-cultural groups within New Zealand will prefer or choose traditional rather than conventional treatments in the treatment of their children's' illnesses that are based on their own cultural beliefs and practices.

Psychological factors

Stressed parents may be seen by health professionals as being unable to reason effectively under the immense strain of their child's life-threatening condition and the need to decide to respond to medical requests for tests, treatment and sometimes drastic intervention. Several factors are at play. These factors include anxiety over the child suffering severe pain from the treatment, a desire for better and less complicated treatments, lack of empathy from health care professionals, and misinterpretation of improved prognostics (Yeh, Lin, Tsai, Lai & Ku, 1999). Others include self doubt, guilt, panic and uncertainty about the long term effects of treatment. Indeed, as any brief examination of a cancer related message board/open discussion website will reveal, cancer causes massive anxiety for all concerned (American Cancer Society, 2006). On such sites, it is quite common to see a large number of psychological concerns on such sites that are headed "what is worse, chemo or no chemo?", "scared", "need more info please", "terrified" and many more. It is no surprise therefore that psychological turmoil is common for the parents of children with cancer because faced with the possible death of one's own child, such anxieties are both daunting and at times, unbearable. That parents are expected to decide on behalf of their child whether or not to accept significant medical treatment decisions, such as the use of

³⁶ This thesis takes the broad view that "... culture should be regarded as the set of distinctive spiritual, material, intellectual and emotional features of society or a social group, and that it encompasses, in addition to art and literature, lifestyles, ways of living together, value systems, traditions and beliefs". (UNESCO, 2002. *Universal Declaration on Cultural Diversity*).

chemotherapy, or radiation therapy or surgery, during such a time is also of considerable significance.

Ignorance, neglect, and/or malice

According to Brody and Engelhardt (1987), both lecturers in bioethics at a College of Medicine, there are some parents who will avoid seeking medical assistance on behalf of their minor children because of either a lack of sensible consideration for their welfare, or because they cannot be bothered to care for them, or even out of a malicious intent to harm their own child. The notion of child abuse is therefore not too far removed from such a position, and subsequently, ignorance or neglect may quickly become a legal matter if the life or welfare of the child is thought to be at stake (Reece & Ludwig, 2001). In this regard, the state is seen to act to protect the rights and interests of children in nearly all suspected cases of parental abuse, neglect, and ignorance. However, because it is well recognised that parents who hold, for instance, particular religious viewpoints may refuse medical interventions on such grounds, the law normally attempts to separate parental motives into either understandable and explainable reasons or motives versus cruel and/or abusive or neglectful reasons.³⁷ 'Ignorance or neglect' therefore often stands as a legal yardstick by which to assess all cases of parental refusal of medical advice.

The above outline of the 'causes' of parental resistance is not exhaustive, but if anything is to be gleaned from a preliminary examination of available literature, it is that the representations of the causes of parental resistance to medical treatment are nearly all based upon expert or professional opinions from within medical texts or academic research (Brody and Engelhardt, 1987; Cant & Sharma, 1996; Eisenberg, Kessler, van Rompay, Kaptchuk, Wilkey, Appel et al. 2001; Yeh, Lin, Tsai, Lai & Ku, 1999).³⁸ Some, such as the studies performed by Yeh, Lin, Tsai, Lai & Ku (1999) and Eisenberg et al (2001), are theorised from (mainly empirical) research based findings which have often involved surveys; others are based on qualitative studies, such as those studies performed by Young et al (2002), which lend background credence to ideas about parental resistance. However, further explanation of the causes of resistance that take alternative perspectives seriously, and include parents' *perspectives* is needed. As Irwin and Jordan (1987) note:

A consequence of the legitimization of one kind of knowledge as authoritative is the devaluation, often the dismissal, of all other kinds of knowledge. Those who espouse alternative knowledge

³⁷ See Chapter Five for further discussion concerning the legal responses in the Williams-Holloway and Moorhead cases.

³⁸ Although these perspective are offered in this chapter, considerable differences in the perceived causes of parental resistance are evident when parents are interviewed (see Chapter Six).

systems are seen as backward, ignorant, or naive; whatever they might have to say about the issues up for discussion is judged irrelevant, unfounded, or based on superstition (p.320).

If problems with the parents opposition to treating the child according to 'conventional medical' means are not either fully understood and/or resolved, then both parties may become deadlocked in what may be described as a major clash between the moral (and legal) rights of parents and the responsibilities of medical personnel. Parental or physician resistance may be compounded because the laws regarding the rights of individuals receiving health or disability care do not always clearly help in such situations. This is because, however well meaning those laws are, there is thought to be a 'grey area' which emerges in those cases where parents refuse to co-operate with medical advice and it is thought that the life of a child is at risk. This grey area is a complex and awkward one, largely brought about by continuing difficulties in deciding what exactly the best interests of the child are, and whether or not parents are really being neglectful if they refuse medical treatment for their child. Clearly a number of factors (such as the medical prognosis, the 'odds' for or against a full recovery, the age of the child, and the suggested alternatives) have to be taken into account. This brings into sharp focus the process of decision making in health care settings, and especially those distinctions between notions of an individual, parental and medical capacity to choose and decide.³⁹

Decision making in health care settings

Decision making texts reflect a theorised body of knowledge that is largely peer reviewed by those who possess the appropriate disciplinary status and prestige, and therefore understand the 'rules of engagement' within the field (Bourdieu, 1984). This self-legitimised literature privileges scientific and rational discourses that may be used to control or suppress the responses of others (Foucault, 1977). In such literature, 'decision theory' is applied to situations in an almost calculated and mathematical fashion where there is perceived to be an element of risk, no risk, or an unclear risk. Thus, when 'the rules' (i.e. those rules that are set by the dominant discourse) are applied to medical and legal decision making, the results are remarkably consistent, but when applied to parental decision making, the rules appear to vary considerably depending on the author(s) of the given text and the ways in which the parents are assimilated - or otherwise - within the rules. In some variations, it is often considered helpful for the decision maker to choose alternatives whilst at the same time being constantly mindful of the consequences of their decision (Higgins, 2001; Higgins & Kayser-Jones, 1996; Janis & Mann, 1977). Nevertheless, under the rules, when an individual is deemed to have a sufficient

³⁹ Such distinctions are frequently referred to by Judge's in their remarks on summing up a case involving a child's capacity to consent to treatment (see Figure 5 in Chapter Five, page 126, for an example).

level of understanding to make a legally binding decision, that individual is said to have the “capacity” to choose a course of action and make a decision. In certain circumstances, the individual’s capacity to make decisions for himself may be impaired by lack of intellectual maturity, or a defective physical or mental condition. Decisions are still required however, particularly when they affect the individual’s health and well-being, and/or the desired treatment option offered by physicians.

To encourage and enforce effective decision making between two parties in a health care setting (e.g. patient and doctor), the state provides legal enforcements in the shape of laws and procedures (as previously discussed). This is to ensure that individual choice is supported, *and* to provide doctors with a record of the individual’s acceptance, or otherwise, of a proposed treatment or course of action (Austrin & Phibbs, 1996). In the case of adults, it is held that once an individual reaches maturity, then, extenuating circumstances aside, they have the right to choose for themselves, even if they choose to accept no treatment in the face of an impending health related matter. This emphasis on the individual’s right to make decisions is usually supported in legislation – as the following example from the Queensland Law Reform Commission demonstrates:

Making decisions is an important part of life. It empowers people by allowing them to express their individuality. It enables people to control their lives and gives them a sense of self-respect and dignity. However, for some decisions to be legally effective, it is necessary that the person making the decision has a certain level of understanding. The reason for this is very simple: it is to protect against abuse or exploitation of a person who may be made vulnerable by impaired decision-making capacity. It also helps other people who may be affected by a decision to know where they stand (The Queensland Law Reform Commission, 1996).

In the case of children, the general notion of freedom to choose remains, although there are distinctions made between levels of treatment and the age of the child. A three year old cannot be said to be fully aware and equipped to decide whether to accept life saving treatment or undergo a major operation, but the wishes of competent older children regarding their medical care are expected to be taken seriously. Accordingly, as state sanctioned controllers of the law, the physician or other health care worker may judge a child competent to make a medical decision; if then the child refuses medical treatment, it is normally expected that ‘further discussion is necessary’, as is encouraged in any adult decision making scenario where refusal is unexpected. It is normal practice in the case of young children (tentatively around 7 years and under), that the decision maker will be a surrogate one, usually parents or guardians. Overall, the law recognizes a hierarchy of family relationships in determining which family member should be the official “spokesperson,” though generally all close family members and

significant others should be involved in the discussion and reach some consensus.⁴⁰ In those cases that require parental consent, the individually focussed autonomy-preserving process may be a cause for concern, especially when parents refuse the offer of medical treatment on behalf of their child. There is, for instance, a tension between the deeply personal relationship between parent and child, and the professional relationship between parent, child and physician (Murray, 1996). This tension is, as Austrin and Phibbs (1996) imply, indicative of the both way those relationships are regulated by the State, and the difference between the importance placed upon individual consent and collective trust. In the latter case, parents are forced to decide as if they were the individual concerned, whilst at the same time trust in the collective wisdom of medicine supported by the law. Furthermore, the field, capital, and habitus of the parents' world may be significantly different from that of the physician or the lawyer (Bourdieu, 1984). Such differences may lead to misunderstandings, mistrust and even radical resistance from parents when making an important decision regarding a child's future medical treatment, especially a decision that involves 'life and death' outcomes.

The concept of an individual's 'capacity to choose' in law

In common law an adult has full capacity to decide for him or herself, unless it is shown that he or she does not because of their circumstances. Present laws offer a number of tests of capacity depending on the type of decision in issue; individual statutes contain provisions on capacity, and case-law provides answers in other circumstances. Nevertheless, there are distinctions between the *legal* concept of capacity or incapacity and the *medical* concept of capacity or incapacity, and there are instances where these two concepts may clash when one type of capacity to choose is challenged by another.⁴¹

A legal incapacity is thought to arise whenever it is considered that a person is incapable of taking a particular decision, undertaking a particular juristic act, or engaging in a particular activity. Incapacity can arise from a variety of conditions that include being under the age of majority or of unsound mind. Under modern law, a great many different approaches have developed to the question of capacity based on mental state, and capacity is judged in relation to the particular decision or transaction involved. There is also a basic common law test of

⁴⁰ The hierarchy for surrogate decision making is as follows: 1) Legal guardian with health care decision-making authority, 2) An individual given durable power of attorney for health care decisions, 3) a spouse, 4) adult children of patient (all in agreement), 5) parents of patient and 6) adult siblings of patient (who are all in agreement) (School of Medicine, University of Washington, 2004).

⁴¹ As in, for instance, the disastrous results of differing interpretations of an individual's legal freedom to choose versus medical interpretations of that capacity in a recent drug trial in the United Kingdom ("Drug trial four are conscious", 2006).

capacity, which operates on the level that the person concerned must at the relevant time understand in broad terms what he is doing and the likely effects of his action. Thus, in an overall sense, legal capacity depends upon understanding rather than wisdom; the quality of the decision is irrelevant as long as the person understands what they are deciding. This basic test has been adapted *ad hoc* to meet specific situations and the precise test now employed by the common law or statute may differ according to the situation and country of origin.

A medical incapacity to choose is thought to rest more upon judgement based around the notion of what an informed person would choose based upon a number of variables, such as the state of consciousness or awareness of the individual, their age, and in particular, their mental state (The English Law Commission, 1991). Yet, physicians are urged to avoid confusion with legal jargon in decision making circumstances, and use the phrase “decision making capacity” rather than legal capacity. Furthermore, the definition of an ‘informed person’ (or in New Zealand, an informed ‘reasonable consumer’) may be perceived as one thing in a legal sense, i.e. “Before making a choice or giving consent, every consumer has the right to the information that a reasonable consumer, in that consumer’s circumstances, needs to make an informed choice or give informed consent” (Right 6, Code of Health and Disability Services Consumers’ Rights Regulations, 1996), but another thing in a medical sense. That is, the physician’s understanding of what ‘information that a reasonable consumer’ might require could vary considerably, and therefore affect what actions he may or may not take on the strength of it. Subsequently, in practice, errors can occur. This state of affairs may be further complicated in medical emergencies or when the ‘reasonable consumer’ is a child and/or her/his parents.

Whilst legal definitions of both capacity to choose and informed consent are considered relatively transparent, medical interpretations of those definitions may vary (i.e. generic standardisation is an attempt to remove variability, but medical standards operate to highlight variability – which is often the result of contextual differences). Yet, in medical practice, valid medical decisions are required every day, and physicians are under continuous pressure to prove certainty often in the face of uncertainty. Such pressure is considered a professional norm in relation to the perceived role of the physician in society, and as such, there is a considerable amount of medical literature devoted to the subject.

Representations of medical decision making

Medical representations of decision-making tend to present as a mixture of both old and new ideas taken from both medicine and decision making research (Sox, Blatt, Higgins & Marton, 1988). Subsequently, medical literature offers extensive commentaries reflecting various shades of philosophical, theoretical and practice based opinion (Brock and Wartman, 1990; Chewing & Sleath, 1996; General Medical Council, 1998; Higgins, 2001; McNeil, Pauker & Tversky, 1988; Riemenshneider, 1986; Savulescu, 1995; Wulff, 1995). In an era where the belief that ‘doctor

knows best' seems to be waning, there remains a considerable degree of trust in members of the medical profession to make the right treatment recommendations on behalf of their patients. This is the case even though most of the mystique and controlling mechanisms of medicine in the last few decades have been challenged by a series of post-structuralist critiques (Lupton, 1994a),⁴² and a number of high profile public scandals involving medical personnel (Phibbs, 2000). Instead, it is argued that in medical decision making, there is a new era of compromise or even client-led models (Savulescu, 1995). Yet, as physicians are still recognised as possessors of 'authoritative knowledge' (Irwin & Jordan, 1987), they maintain a relationship of power (which is arguably of fluctuating intensity) between themselves and their patients. Such a relationship is based on the notion that it is in the 'best interests' of the collective social body that physicians both gain and exert professional power, which is itself based on the longstanding belief that doctors use this power to act in the 'best interests' of their patients (Parsons, 1951).⁴³

The concept of 'best interests'

As medical knowledge is historically and culturally constructed (Foucault, 1975), the basic goals of medicine are still associated with a four hundred year old pledge: "To cure sometimes; to relieve often; to comfort always" (Anonymous, 1993). This traditional discourse is now represented in more modern terms - to cure if possible, or to palliate symptoms, prevent disease or disease complications, or improve functional status. If none of these goals can be achieved, then in many cases, the treatment may be seen as 'futile'; alternatively, if any of the above goals were seen as achievable, or even possible, then medical treatment would be seen as valuable and 'in the best interests' of the patient. Hence, treatment withdrawal by the physician would be justifiable if the treatment no longer benefits the patient or if a competent patient no longer wanted a treatment, irrespective of whether or not it would then be seen as in their 'best interests' (General Medical Council, 1998). In both cases, 'best interests' could conceivably include death, as was legally argued in the Baby L case (see Chapter Five, pp. 138-139 for further discussion). In medicine, a competent person is someone who is able to comprehend relevant information, weigh up the benefits and risks of proposed procedures, reach a 'reasonable' decision, and understand their own situation and is able to pursue their own goals (Sainio, Lauri & Eriksson, 2001).

⁴² Including Foucault's (1975) own powerful critique of "the myth of a nationalized medical profession, organized like the clergy, and invested, at the level of man's bodily health, with powers similar to those exercised by the clergy over men's souls..."(p. 31).

⁴³ Western medical ethics, and the decisions therein, have been based primarily on the Hippocratic tradition, which required the physician to do what is considered necessary in the patients' best interests.

But what is a reasonable decision? The decision making process for an adult has to be judged as sound even if doctors may not agree with the decision made. Another level of complexity is added in the case of children as in law a physician is also an advocate for the child. In this case, a reasonable decision has to concur with the physician's view of what is reasonable and realistic in the given circumstances. This tension between individual rights and collective regulation of decision making /informed consent is thus played out in the physician's relationship with the parents. In the case of children, 'best interests' discussions in the New Zealand literature and guidelines for practice are a mixture of medical and legal standards, but the anomalies between legal and medical standards means that in difficult cases, such as those involving young children and their parents who resist medical treatment, physicians are obliged to seek guidance not only from legal sources, but from multidisciplinary ones as well (Pinnock & Crosthwaite, 2005). Paediatricians are encouraged to refer to medical codes of practice and ethics, and similar documents for guidance (such as may be found in the recommendations of the Paediatric Society of New Zealand and the Board of Paediatrics and Child Health of the Royal Australian College of Physicians, 2001). In these documents, discussion concerning parental/medical disputes and the 'best interests' of a child are of central concern; in such cases, doctors are offered the warning that the 'best interests' argument should not be used 'manipulatively and coercively' by themselves and that individual and cultural differences may make a difference. This notion is reflected in advice for physicians that is produced by their own professional bodies:

It is for the patient, not the doctor, to determine what is in the patient's own best interests. ... you may wish to recommend a treatment or a course of action, but you must not put pressure on patients to accept your advice (General Medical Council, 1998).

Considerable care is taken in the document to emphasise the impact of age differences in children, i.e. that whilst most children under ten lack the competence to give informed consent, those who are older are expected to have views and to have them respected. 'Expert assistance' is recommended from child psychologists and psychiatrists to determine the level of the child's understanding and competence to make decisions.⁴⁴

Nevertheless, 'best interest' standards concerning children are complicated for doctors because, according to Carnevale (2005):

...it is difficult to determine which benefits and burdens are most significant; [3] it is problematic for a parent to distinguish the child's interests from the parents' own interests; and [4] questions can be raised about whether the interests of others (e.g. well siblings) are necessarily secondary to those of the patient (p. 241).

⁴⁴ Similar guidance is offered to American or Canadian pediatricians (Carnevale, 2005).

New Zealand paediatricians are aware of the legal standards of best interests because they are widely used by child welfare services and family court systems (see later discussion) in situations where the usual providers for children - their parents - are no longer able, or willing, to do so.⁴⁵ In these cases, doctors and welfare workers co-operate together through the courts reflecting their part in the state's role of surveillance and control (Foucault, 1977).

In legal interpretations of what may be in a child's best interests, courts usually rule in favour of those who present a case that is thought to be the least psychologically traumatic for the child, and, of course, at the same time life preserving. It is in such situations that some parents have legally lost control over their own child's immediate destiny to physicians. Medical control of decision making in the best interests of the patient is therefore both accepted and expected (Bourdieu & Passeron, 1977; Giddens, 1979).

Medical decision-making models

In medical literature, the range of medical decision-making models extends from old fashioned paternalism to the more recent culturally focused and autonomy promoting shared decision-making. There follows an overview of the main examples:

The paternalistic model

Many physicians remain in practice today that were trained along the lines of a traditional model of consultation, in which the patient's only active contribution to the conversation is to present and describe their symptoms for the medical gaze (Foucault, 1975). This situation was not only accepted by physicians, but by their patients as well (Riemenshneider, 1986). Paternalistic behaviour in medicine is now thought to indicate that value judgements are made and justified through sets of understandings about what is 'medically indicated' which would have been more properly made by the patient (Savulescu, 1995). That is, the doctor may 'know' the physical facts, but not the personal, value laden ones; but can the two, factual and value laden, be separated anyway? In the western world, the greater emphasis on neo-liberalism in the latter part of the twentieth century demanded change from either 'the state/authority figure knows best' to a more 'the individual knows best' mentality, which has resulted in a number of changes to patient expectations, legislation, and medical practice. The growth of medical technologies that require the patient to administer their own treatment at home has further diminished the institutionalised power of the physician to a certain extent. Hence, newer models

⁴⁵ Legal frameworks for these standards are based upon psychological theories and research (Banach, 1998) which are attachment theory, maternal deprivation research and resiliency theory and research. Attachment theories are attributable to Bowlby's ideas of attachment (1940, 1979, 1980) and Ainsworth's longitudinal studies on the different phases of attachment (1982).

of medical decision making have emerged in the last few years, including the 'partnership model'.

The partnership model

This model relies upon the ideals of an equal partnership between the medical profession and the recipients/s of care. Because many patients now wish to have a greater level of involvement in decisions about their care, and the paternalistic model has been found wanting in recent years, this model has become a more common norm in health care (Editorial, British Medical Journal, 1999). That patients should be more active partners in decisions about their care is now accepted as public policy. For instance, in the United Kingdom's National Health Service Executive's Patient-Partnership Strategy (1999), it is maintained that achieving a successful patient partnership requires that patients are given the information that they request about their condition and their care ensuring that they are treated with respect and as partners in their care (Department of Health, 1999). The partnership theme for medical decision making has been taken up in similar ways in New Zealand:

The nature of the doctor/patient relationship has been under scrutiny, and undergoing change, for the last decade or so. Medical professional dominance is giving way to the model of partnership and patient empowerment - where patients have access to information and are involved in decision-making processes about options for their own health care (Researched Medicines Industry Association, 2001).

The partnership model is now reflected in the training of physicians, in which the patient and doctor meet as equals, but with different expertise. In this model of partnership, the structure of the consultation changes and power within the relationship becomes more evenly shared. For instance, in the editorial in the British Medical Journal (1999) it is argued:

Partners work together to achieve common goals. Their relationship is based on mutual respect for each other's skills and competencies and recognition of the advantage of combining these resources to achieve beneficial outcomes. Successful partnerships are non-hierarchical and the partners share decision making and responsibility. The key to successful doctor-patient partnerships is therefore to recognise that patients are experts too. The doctor is, or should be, well informed about diagnostic techniques, the cause of disease, prognosis, treatment options, and preventive strategies, but only the patient knows about his or her experience of illness, social circumstances, habits and behaviour, attitudes to risk, values, and preferences. Both types of knowledge are needed to manage illness successfully, so both parties should be prepared to share information and take decisions jointly (pp. 719-720).

For the parents of seriously ill children, partnership approaches are desirable, but still not always in evidence. For instance, in the Bristol Royal Infirmary Inquiry⁴⁶, the conclusion stated

⁴⁶ This major inquiry related to "the management of the care of children receiving complex cardiac surgical services at the Bristol Royal Infirmary between 1984 and 1995 and relevant related issues...to establish what action was taken both within and outside the hospital to deal with concerns raised about the surgery and to identify any failure to take appropriate action promptly; to reach conclusions from these events and to make recommendations which could help to secure high quality care across the NHS" (Terms of reference, Bristol Royal Infirmary Inquiry, 2001).

that there needed to be changes in the attitudes shown by healthcare professionals towards patients and particularly parents. Parents emphasised the need for them to be involved in their child's care and for a greater acknowledgement and engagement of their expertise (Bristol Inquiry, 2001). The Bristol Inquiry suggested that parents wanted to be closely involved in the care of their children, and to participate as consultants or experts in the care of their own child rather than as bystanders, but did not always feel able to do so through lack of participation or involvement (for which there is another model).

The participation - involvement model

In this model, patient participation may be described as a multitude of complex variations between two poles that range between the paternalistic 'doctor knows best' position (where the patient allows an authority figure such as the doctor to make the important decisions), to an almost opposite situation where the patient makes almost every decision for themselves (a 'client centred model'), with the doctor providing information as required (Chewing & Sleath, 1996). In the latter case, this model best matches the home dialysis situation, where the treatment and management of the condition is given over almost entirely to the patient. In most present day situations, some degree of patient participation in choosing and consenting to a particular treatment or action is expected as the norm, a position that is generally supported by both legislation (Rights 5-7 in the code of Health and Disability Services Consumers' Rights, 1996) and by ethical codes or standards (as in the New Zealand Nurses Organisation, Code of Ethics, 1995; or the Code of Ethics of the New Zealand Medical Association, 2002). By and large, much participative decision making is associated with patients responding to medical decisions (Avis 1994; Deber, 1994; England & Evans, 1992), but there are examples of patient responsiveness to nursing decisions also (Biley, 1992).

An important element of any participation or involvement model includes the sharing of information and the patient's capacity to understand the information and manage the treatment that is offered. In both cases, the patient's position may be affected by difficulties in understanding information, fear and anxiety (Beaver, Luker, Owens, Leinster, Degner & Sloane, 1996; Hughes, 1993; Krishnasamy, 1996; Mackillop, Stewart, Ginsberg & Stewart, 1988). It is also necessary that a sense of trust exists between the physician as deliverer of medical information, and the patient as the recipient of the information to be able to feel confident enough to respond and act accordingly (Brennan, 1997). Overall, it is thought that encouraging patient participation in decision making has a positive impact upon the process (Blanchard, Labreque, Ruckdescher & Blanchard, 1988; Davidson, Joyce & Degner, 1997; Lauri & Sainio, 1998; Tronobranski, 1994) but others have noted a negative effect, where the promotion of patient involvement in decision making has led to mixed conclusions about overall (medical) effectiveness (Entwistle, Sowden & Watt, 1998). Such a state of affairs is therefore not entirely

satisfactory, and perhaps it should be remembered that in some cases (for instance, the ‘Baby L’ case as outlined in Chapter One) this approach simply does not work. Under such circumstances, yet another model has been designed to reflect the present day requirements of ‘health care consumers’ in a more direct and shared fashion.

The shared decision making model

In this model, there is an agreement to share everything as equally as possible between doctor and patient. According to Brock and Wartman (1990), physicians bring their medical training, knowledge and expertise, which includes their understanding of the available treatment alternatives, to the diagnosis and management of the patients’ conditions; patients bring knowledge of their own subjective aims and values, through which the risks and benefits of various options are calculated. It is an approach that requires the selection of the best treatment option by both parties where the doctor is basically an objective fact-provider only, (but in providing the facts, is the doctor not also providing either overt or covert value statements as well?) and the client provides their own subjective viewpoint. This approach, prioritises consumer rights and responsibilities, may therefore be preferred over others; but it remains pertinent to note that in both the way information is passed on, and the very presumption that the physician has all the ‘facts’ (i.e. knowledge), can influence the way that it is received and given significance. For instance, if a doctor offers a choice that is framed in terms of loss, it is perceived that there is an element of ‘risk taking’, but when it is framed in terms of gain, it is suddenly ‘risk-averse’ (Tversky & Kahneman, 1981) - the use of hormone replacement therapy (HRT) in menopausal women may be a moot example. This interesting phenomenon is termed ‘the framing effect’ and it therefore begs the question that the decision making may not actually be shared at all.

In the case of parental involvement in the shared decision making model, Rushton (1994) states that parents are actually undergoing a process of self-perception (i.e. ‘being a good parent’) which may not necessarily concur with the physician’s objective perspective either in full, or even at all. The parents perspective on what is best for their child, based as it is on their relationship, and their understanding of being parents, may be significantly different from the physicians (Gafni & Whelan, 1997; Gwyn & Elwyn, 1999; Stiggelbout & Kiebert, 1997). This situation was a central issue in the case of Liam Williams-Holloway’s parents’ decision to reject medical advice (as outlined in Chapter One). Thus, it may be argued that no particular approach to medical decision making in health care is without problems.

To conclude, there are several models of medical decision making, but none are seen as being perfect. Yet, as the Bristol Inquiry noted, parents are still not entirely convinced that they are able to take part in medical decision making concerning their child in a fashion that is balanced and reflective of their expertise. Subsequently, and as this thesis maintains, there are

still incidences of parental unease, disagreement, and resistance. Such resistance has to begin at some point in the relationship between physician and parent, and as it was found in the five cases (previously noted in Chapter One) resistance revealed itself when the parents of a seriously ill child were asked to provide informed consent for medical interventions. Parental refusal to give consent therefore triggers a medical search for reasons, and suitable ways to respond.

Representations of parental decision making

According to the medical profession, parents have the responsibility and authority to make medical decisions on behalf of their children (School of Medicine, University of Washington, 2005). This includes the right to refuse or discontinue treatments, even those that may be life-sustaining. It is also maintained by the same professional body that parental decision making should be guided by the best interests of the child and that these interests are most understood by those who care for the child, i.e. the parents. As Blustein (1993) argues, the involvement of family members in health care decision making should be given medical priority because it is recognised that many medical decisions will also affect the child's family; therefore parents should be allowed to introduce family issues and values into medical decisions about their children.⁴⁷

Yet, it is also maintained in medical texts that decisions that are seen by the physician to be against a child's best interest, can (and should, it is argued) be challenged (Braddock, 2004). The challenge by the medical profession to those decisions by parents thought not to be in the child's best interests is based on the notion of 'medical caretakers' having a legitimate, authoritative, objective, ethical and legal duty to advocate for the overall good of child (Campbell et al., 1997). It is also based upon the notion that medical knowledge is 'authoritative knowledge' in as much as it is considered in the community to be "legitimate, consequential, official, worthy of discussion and useful for justifying actions by people engaged in accomplishing a certain task or objective" (Irwin & Jordan, 1987, p. 319). Parental knowledge, on the other hand, is viewed as being less authoritative, and therefore in matters of important health related decisions, is biased towards their child, or to themselves, or the entire family. This is especially so when it is considered *by medical authorities* that the parental decisions are potentially dangerous to the child's health, imprudent, neglectful, or abusive. When satisfactory

⁴⁷ As previously noted, it is also a widely held belief, at least in medical and legal texts, that children with the developmental ability to understand what is happening to them should be allowed to participate in discussions about their care. This capacity is thought to increase as children become older, until adulthood, when the choice is entirely theirs by right and usually by law.

resolution cannot be attained through 'respectful discussion' and ethics consultation, a court order for appropriate care is deemed necessary.

Although there is literature to support the view that parents are considered to be the best sources to decide on what may or may not be in a child's best interests (Blustein, 1993; Ross, 1999), it is also recommended that if, according to the doctor, the parents do not appear to be acting in the child's best interests, the doctor should attempt to override the parents' decision. In practice, this creates a binary opposition because doctors are expected to respect parental autonomy on the one hand, but reject it on the other if, and when, the doctor does not trust the parents' decision making capabilities, or their decision. As Austrin and Phibbs (1996) suggest, choice in health care decision making appears to be an individual property (consistent with neo-liberalist ideology), but when deemed to be the wrong choice, actions are sometimes taken which indicate that decision making is also a collective property regulated through state mechanisms (as previously described). Things can therefore go awry for parents if it is felt by physicians that they have made the wrong decision concerning the acceptance or otherwise of medical treatment for their child.⁴⁸ It may be argued that whilst lip service is paid in a legal and medical sense towards parental authority to choose for their own children, in practice (at both medical and legal levels), parental autonomy to choose on behalf of their own children may be successfully challenged if, and when, that choice is not in agreement with the views of the physicians and/or the legal system. This suggests that the concept of parental autonomy is complex and contradictory, necessitating negotiation and compromise.

The concept of parental autonomy

Buchanan and Brock (1989) maintain that "the interest of the parents in making important decisions about the welfare of their minor children...has not been sufficiently appreciated in literature...or in health care practice" (p. 226).⁴⁹ They argue that parents should be the surrogate decision makers for their children because children need a surrogate and because the parents

⁴⁸ There are (less common) instances when other members of the medical profession are sometimes unhappy with the decisions of their peers, and even supportive of the parents' right to decide: "The Court of Appeal decision to allow the operation to separate the Siamese twins is unethical and wrong, according to an expert ...Professor Gillon said he personally would give the go-ahead to an operation if he was in the same position as the parents. But he added that the court should only have taken the parents' views into consideration, regardless of what they were..." ("UK ethics expert: twins decision wrong," 2000).

⁴⁹ Ross (1999) tends to agree overall, and actually opposes the current movement to increase child autonomy, in favour of respect for 'family autonomy'.

have a legitimate interest in making decisions for their children. Four reasons are offered in support of this claim: a) Most parents care deeply about their own children's welfare and know the child's needs better than others; b) parents will bear the consequences of their decisions or treatment choices; c) parents have the right to raise their own children according to their own standards and values, and to seek to transmit these to their children; d) the family is a valuable social institution, especially in its role of fostering intimacy. As such, this role requires freedom and/or privacy within limits.

In seeking to determine how decisions ought to be made for those unable (not competent) to make them for themselves, Buchanan and Brock (1989) maintain that there are three most popular guiding principles for surrogate decision making (advanced directives, substituted judgement and best interest standards). Subsequently, and because children have never been competent (as opposed to the other possibilities), they suggest that best interests standards should apply to children. They offer three types of cases:

- a) Those that disqualify the parents as surrogates, i.e. "abuse, neglect, incompetent parents, or parents who have a 'serious conflict of interest which is likely to bias their decision against the patient's rights and interests."
- b) Cases deserving special scrutiny, i.e. "by virtue of the especially vulnerable position of the incompetent patient, the momentousness of the consequences of the decision, and/or the especially high likelihood of conflicts of interest between patients and surrogates (as an example, organ donation by incompetents)"
- c) The substance of the decisions, i.e. "the treatment must be within the range of medically sound alternatives as determined by appropriate *medical community* standards" (pp. 142-143, italics added).

Buchanan and Brock argue that failure on the part of the parents to intervene is not an adequate reason for medical intervention because the best interests principle serves only as a regulatory ideal and not as a literal requirement; the parents may have other children to consider, as well as other legitimate self interests that prevent the maximisation of that child's interests. Of even greater interest, they claim that parental authority should be respected *even if the parents decision is not the best available* because it is against the child's interests to compel parents by means of state control; although state intervention is always a possibility in cases where parents are failing to provide or promote the child's basic needs.

Nevertheless, many parents may readily accept the hegemony of biomedicine because they are more than willing to defer to the 'higher authority' and wisdom of the physician which is for the most part is an expectation of society (Bourdieu, 1984) and an anticipated norm within the health care system (Lupton, 1994a). Few parents would choose to jeopardise their own child's welfare when they themselves cannot meet their needs, and will therefore readily comply. That some do not comply, by rejecting the medical viewpoint and refusing medical treatment for their child, implies that they also reject the authoritative knowledge of physicians and face 'more coercive means' that may be employed to support medical authority. It is at such times that "the logic of the power relations inherent in authoritative knowledge as well as the process

of creating that logic anew” (Irwin & Jordan, 1987, p. 320) predominates. Parental choice in decision making is supported in medical literature, but also challenged in both literature *and practice* (as illustrated in Chapter One) when proposed medical treatment is rejected by the parents.

Summary

Various forms of health related decision making texts have now been examined in this chapter. It has been shown that laws relating to the rights of children and their parents in their own health related matters have evolved over time to the present day neo-liberal viewpoint that holds that individual choice is paramount for patients, children and parents of young children as surrogates. However, in cases where there is parental resistance (especially in the ‘radical’ sense) to medical advice, and parents reject or stall medical advice and treatment, doctors are also advised to act, through the law if necessary, to protect the best interests of the child. In doing so, a noticeable degree of ‘body politic’ based conservatism seems to prevail, and medicine and law combine in a pincer movement against such parents if deemed necessary. This is largely because ‘authoritative’ medical knowledge is viewed as more powerful than other types of knowledge (Lupton, 1994a). Such knowledge offers a seemingly accurate explanation of a given (medical) situation and its ‘remedy’ (Foucault, 1973) and it offers a superior ‘structured structure’ (Bourdieu, 1977a). In this fashion, it is persuasive not only because it seems reasonable, but also because it includes a veiled threat of powerful sanctions (Irwin & Jordan, 1987).

An examination of established medical and legal texts suggests that children’s rights and parental and medical responsibilities are significantly proscribed in this country by legislative frameworks. Within these rigid frameworks lies a number of dichotomies and challenges for both doctors and parents alike. For instance, there are obvious pressures on doctors not to be criminally negligent in their provision of care, but at the same time to ‘allow’ a considerable degree of autonomy to their patients. Other health care providers, such as nurses and midwives, are covered by similar requirements. Nevertheless, because informed consent depends upon a high degree of trust between physician and patient (or parent), and ‘medical matters’ are beyond the usual scope of most patients, the doctor’s role is constructed as one of guidance and counselling towards the ‘right decision.’ Such a decision, as argued previously, is meant to be in ‘the best interests’ of the patient. In regard to a proposed treatment for a seriously ill child, the parents’ role is to deferentially accept that advice and help with the care of their child. Subsequently, there are consequences for those who do not choose to follow this guidance, and these may include the parents being labelled ‘non-compliant’ or ‘difficult.’ These labels impact not only on the relationship of the parents of a child patient with the initial physician, but

sometimes, even often, with the relationship of the parents with other physicians as well.⁵⁰ The situation, in regard to the doctor-patient relationship, is described thus:

Many physicians enter medicine with the goals of solving medical problems and curing disease. They do not expect to encounter patients who make repeated visits without apparent medical benefit, patients who do not seem to want to get well, *patients who engage in power struggles*, and patients who focus on issues seemingly unrelated to medical care. Whatever the causes of these problems, the results are similar: distraction from effective care, waste of physician energy, complaints from patients and staff, and continued health problems for the patient (Haas, Leiser, McGill & Sanyer, 2005, p. 2063, italics added).

In such situations, it is as if the patient/parent has ‘broken the contract’ or become resistant to ‘sound advice’, and is no longer a reliable or compliant individual. Thus, in cases where there is a *fundamental disagreement* on treatment objectives featuring a breakdown of trust and informed consent between physician and parents, then it is often the law that is used to resolve the difficulties. At this level, issues of trust and informed consent become highly individualised as resistance complicates the norms of engagement within the physician-parent relationship.

The legislation surrounding informed consent implies a number of discursive themes, all of which are connected to norms within society that each individual must attain or at least aspire towards. These themes include the need for rationality and reasonableness, which, according to Bourdieu’s view of habitus (as types of “behaviour that go without saying”), are attributes of a particular social class or group; that is, rationality is ‘socially bound’ (Bourdieu, 1984; Bourdieu and Wacquant, 1992). The legislation that surrounds informed consent is constructed around those who fit into a predominantly ‘mainstream’ habitus and are capable of fully responding to the ramifications of rationally focussed informed consent. Any parents that trouble the state and its relationship with individuals in society by refusing a medical service that is normally considered to be both rational and desirable (as a natural extension of the body politic) are therefore challenging not only the doctor, but the state itself. Subsequently, such challenges do not go unrecognised, and both the media, as a recorder of state actions, and the law, as the standard setter and enforcer of state control, roll into operation. In the next two chapters, the discursive elements and practices within these processes will be explored in detail.

⁵⁰ There are also consequences for parents who initially follow the doctor’s advice and decide in hindsight that it was not the best decision in the interests of the child.

CHAPTER FOUR

Media representations of parental resistance

Sympathy for Liam's parents must not be allowed to cloud the fact that in the end the medical professionals were right. He lived much longer than the three to six months they gave him if he went without chemotherapy. But he died, as they said he would, after the withdrawal of medical treatment. The alternative therapies his parents tried did not heal him. That is the plain truth of it, and any parents in a similar predicament should face the fact (Editorial, New Zealand Herald, 2000).

Introduction

In this chapter, the role of the media in shaping public opinion⁵¹ about parental resistance is explored through the examination of a number of texts produced within the last decade in newspaper and magazine articles, internet websites, and radio or television interviews. The purpose is to highlight representations of key themes in the mass media concerning parental resistance. Overall, it is argued in this chapter that in matters concerning (legal) cases of parental resistance, the media presents 'mainstream' values with the consequence of promoting medical and legal opinion but demoting any opinions that significantly differ in outlook. It is also maintained that the media attempts to influence public opinion concerning parents who resist medical advice and treatment for their children by adopting particular representations of those parents that are based upon differences and 'otherness'.

The chapter begins with an overview of the role of the media in New Zealand, and includes discussion concerning the power of the media, the ways in which the media discursively frames cases of parental resistance, and the methods used by the media to influence public opinion. The chapter then concentrates on media representations of parental resistance which illustrate the assigned roles and expectations of children, doctors, parents, the law and even the media itself in various forms, which in the case of resisting parents ranges from 'culturally different' to misguided or misinformed to ignorant or malicious.

This chapter is supported by relevant theoretical ideas of Foucault (1973, 1975, 1979), especially those ideas relating to the uses of power (1977, 1980a, 1991) and how it may be exhibited within dominant discourses, such as those found in institutions. Foucault maintained

⁵¹ It is accepted in this thesis that the degree by which the media may effect public opinion rests on the very idea of public opinion itself. The Anglo-American tradition sees the media as contributing to social reality through the reproduction of ideological contents generated elsewhere – especially by the State (Kellner, 1995); but the (poststructuralist) French tradition veers more towards explanations that challenge the notion of a singular 'public opinion'. For instance, according to Champagne (1990), public opinion is an imaginary or utopian concept that serves as a legitimising principle for political discourses and actions.

that meaning was socially constructed by institutions, including those media institutions that Bourdieu (1998b) also criticised, the television networks, publishing houses and newspaper chains. Bourdieu's (1973, 1977b, 1984, 1990a) ideas on the uses of metacapital within specific fields is therefore relevant in this chapter also. Nevertheless, the chapter is specifically guided by the ideas of Lupton (1994a, 1994b, 1995, 1999) and Lupton & McLean (1998). Lupton's work in the field of media analysis and its relationship to medicine, illness and disease, uncovers 'latent' or 'sub textual' discourses. Her approach relates to Foucault's (1970, 1972) 'method' of examining constructions and 'constructed' texts, being more analytically critical than traditional methods of media analysis.⁵² Lupton delves into 'hidden' textual inferences and surfaces those elements that might not otherwise be fully appreciated, such as dominances, contradictions and ambivalences within the discourses. In particular, Lupton highlights an obsession with binary oppositions in the press such as notions of 'heroes and villains', or as is argued later in this chapter, of knowledgeable and trustworthy physicians as opposed to ignorant and/or misguided patients. The 'heroes and villains' discourse may be seen as a common feature of modern society; it is a widespread phenomenon in current interpretations of history and even the present (Lupton, 1994b). This is because heroes and villains are 'figural actors' that occupy space within the (discursive) field and are defined by the structural features of that field (Bourdieu, 1984). Heroic figures are familiar cultural tropes that provide models or modes of thinking, acceptable ways of behaviour and possible solutions for existing problems (Wuthnow, 1989). Yet, the creation of binary divisions within the press is an oversimplification of complex issues, and therefore liable to public misinterpretation as decisions are made about whether to accept or reject the given media coverage.

This chapter contains five main arguments. Firstly, that that journalistic texts go beyond merely reporting 'the facts' and the 'objects' of each case; instead, it is maintained that the media play an integral part in re-presenting socio-cultural and ideological expectations (Bourdieu, 1998b), demands and perspectives on parental responsibility in relation to medical advice for treating a seriously ill child. Secondly, it is argued that the media acts as a major force in the formulation, distribution and direction of public discourses through the selective use of speakers, images and language (Chouliaraki & Fairclough 1999; Fairclough 1989, 1992, 1995; Wodak, 1996). As media discourses are predominantly performed within the public arena, they also influence and shape the construction of social reality. Thirdly, it is argued in this chapter that in the media discourses examined within this research, the media regularly

⁵² Such as those employed by Winston (1990) that provide quantitative or descriptive analyses of media texts, but tend to abstain from socially critical elements.

maintains the soundness of established or traditional medical methods versus the folly of parental resistance towards such methods. Fourthly, it will be maintained that media actively constructs the consensus of opinion through the constant endorsement of traditional medicine and the downgrading of alternative therapies that supports ‘the normal way’ of responding to serious childhood illnesses. Finally, it is argued that medical hegemony within the media versions of social reality in regard to the value of institutionalised health care for seriously ill children is, at times, challenged by what may be seen as marginal discourses from parents and other groups within society (such as alternative therapists or religious sects) which implicitly threaten the status quo. Hence, because the media is the channel where the disagreements between complicated hegemonic and marginal discourses manifest themselves to most public effect, the media plays a significant role in formulating public opinion about parental resistance *of any kind*.

The role of media in cases of parental resistance

To achieve an examination and analysis of media representations of various forms of parental resistance, and to illustrate how the media may influence and shape the construction of public reality, one particular newspaper, the *New Zealand Herald*, has been used as a main source of media related material in this chapter. This newspaper was deliberately targeted because, as Lupton (1995) suggests about the Sydney Morning Herald, “it is the best selling broadsheet in Sydney” [read ‘New Zealand’] (Lupton, 1995, p. 501). The New Zealand Herald’s readership figures of 522,000 are more than double that of the nearest rivals (AC Nielsen, 2000; Newspaper Advertising Bureau, 2000). Other texts extracted from special interest web sites, metropolitan, regional or national newspapers, and major news magazines (as recommended by Lupton & McClean, 1998) are used to give a local, regional or national viewpoint. In an examination of articles reporting cases that involve a high degree of parental resistance to medical advice⁵³, the media presents a series of texts that are complex and contradictory⁵⁴; they are also predominantly supportive of medical advice and intervention and often negative towards those parents that fail to accept such advice.

Media discourses vary from subtle and objective accounts of parental resistance to very personalised and emotive ones (Cleave, 1999, “Parents dice with boy’s life”; Johnston, 2000, “Teen backs chemotherapy”; NZPA, 2002, “Accused told police of Satan’s way”; NZPA, 2005, “Trial highlights clash between parental rights and medical advice”; Taylor & Chisholm, 2000,

⁵³ For the most part, the five cases that are described in Chapter One are used to perform this analysis.

⁵⁴ Bourdieu (1998b) suggests that the media has a selective memory, i.e. that vitriolic attacks against one course of action can suddenly change to support if the tide of public opinion is perceived to change.

“Suffer the little children”; Trevett, 2003, “Police probe death of ‘healed baby.’”). In the latter case, which predominates in the reporting of cases of *radical* parental resistance, ideas about ‘normal’ parental responses are often presented as symbolic or metaphorical self-evident sets of culturally accepted norms along with strategies and practices which tend to legitimise existing doctor-parent-child relationships. For instance, in restructuring complex material to assist in the understanding of difficult concepts, the media may incorporate metaphors or symbolic representations that give the audience an opportunity to examine the issue thereby either accepting it as a good way of thinking about the issue or not. If they accept the metaphor, then they may use it again in their everyday thinking about the issue. If not, then it will be rejected until a more acceptable metaphor is used. Subsequently, there remains a danger of public misunderstanding or even rejection of key, but complicated issues (such as parental resistance to medical treatment for a child), depending upon the use of deliberate symbolism by the media sources relating the material (Fowler, 1991; Lupton 1999). This style of media representation of news events reflects media discourses that are aimed at promoting naturalised and ‘self-evident’ values, attitudes and practices in a fashion that converts people (such as parents and doctors) into symbols or archetypes that ‘stand in’ for wider meanings and concerns (Lupton, 1999). In this way, media supports those attitudes and practices that are defined and maintained by hegemonic devices that are usually readily accepted by the public (Fairclough, 1989, 1999; Fowler, 1991). It may therefore be argued that media has the power to influence the public in ways that are both overt and covert.

The power of the media

The media, as a societal institution, ‘governs’ not only which information the public is to receive, but also ideas about legitimate versus illegitimate courses of action associated with an event. Arguing from the viewpoint of governmentality, Foucault (1991) maintains that major institutions (including the media) exert power and influence on the general populace by means of the adoption of broader strategies in governance both within the organisation and in public.⁵⁵ For Bourdieu (1973), the media, state and other institutions merely compete for meta-capital over specific fields that are themselves nebulous. Nevertheless, Bourdieu was aware of the effects of both global *and* local discursive practices relayed through the media, and how these effects clearly connect to social and cultural practices (Bourdieu, 1998b; also Fairclough, 1995). Hence, the mass media not only provides an overt (but potentially false or misleading) sense of objectivity or cultural ‘normality’, but a covert sense of acceptable and non-acceptable

⁵⁵ For a fuller account of Foucault’s ideas on governance, see discussion on pages 31-32, Chapter Two.

behaviours as well. In this fashion, large media agencies attempt to govern or control the behaviours of their audience, by means of influence and subtle manipulation that may commence with the use of linguistic symbols and end with shaping mass opinion through manipulations of how information is presented, when it is presented, and under which circumstances.⁵⁶ For instance, in the following example, in what appears to be an objective or descriptive report, there are judgemental elements of normal and abnormal behaviours that are supported by the use of certain terms (i.e. the child ‘suffers’; the parents’ actions ‘cut his chances of survival’; medical specialists, through the police and social workers, are forced to ‘hunt’ for the family). Even members of the public are entreated to perform a civic duty by helping to find the family and report them to the police:

The parents of a 3-year-old cancer sufferer are cutting his chances of survival the longer they stay in hiding, say medical specialists. Police and social workers are hunting for Liam Williams-Holloway of Wanaka after a court order granted custody to the state when his parents failed to return from a trip to Auckland, where they had been seeking alternative treatment for him. He has a common form of children's cancer, neuroblastoma, which affects the nervous system, and began chemotherapy at Dunedin Hospital in November. His parents, Brendan Holloway and Trena Williams, had doctors' agreement to take him away for alternative treatment but were due back in Dunedin on January 25. Liam was to have had regular check-ups at the Starship children's hospital in Auckland while away from home. His last visit to the Starship was on January 9 and the family have not been seen since. The Family Court has now granted an application by doctors and given guardianship of Liam to the state youth agency, and, in a rare move, social workers have appealed to the public to help find him (Cleave, 1999).

Opinions differ concerning the overall effect of the mass media; according to one view, “audiences become pawns in the media's struggle for power” (Jones & Jones, 1999, p.188; see also Bourdieu, 1998b). Other viewpoints concerning the role of the media within society range from the media as a powerful influence on society to the media merely competing for attention with other institutions in a competitive market (Couldry, 2004). The news media are partly chronicling current affairs, as they usually claim, but also partly ‘fitting’ these stories into the discursive field (which, in Bourdieu’s [1998b] analysis, is a more general culturally focused environment) in order to seem trustworthy. In this activity, the media must articulate closely enough with their social settings; if they become too close (i.e. too personal), or too distant (i.e. too whimsical), then they may be considered to be either biased or ridiculous. As Foucault (1973) maintains, there are mechanisms within society (such as the medical profession, social work, psychiatry and others) that in conjunction with the popular media provide clarification of the symbolic boundaries between “Us” and “Them”, the licit and the illicit, the mad and the

⁵⁶ As Bourdieu (1996) maintains, the (covert) public effect of the media stretches even farther because the media not only linguistically frames information, but ‘filters’ it as well - in that decisions are made about how much information should be presented to the public, how debates will be structured, what parameters will be employed, and by whom. In this fashion, mainstream media not only selects and presents a multiplicity of media events, but also influences the production of culture.

sane, or in the cases to be described later, the normal parent and the abnormal ones. These norms are defined by reference to the deviant, and there is now little doubt that modern mass media provides numerous examples of normalisation via problematisation. In this regard, it could be argued that the mass media has become a form of Foucaultian 'Panopticon' in that it constantly scans society for signs of deviance with the threat of punishment by disclosure. The greater the public position of the personality, or the more they are in the public gaze, the more likely the media will disclose their activities. In cases involving parents who are taken to court, the greater their resistance, and the consequences of their resistance, the more likely they will be noticed by the media. Furthermore, as if to emphasise the media role in promoting, surveilling and governing normality, the media makes full use of those professionals in society who seek to represent such norms:

The judges of normality are everywhere. We are in the society of the teacher-judge, the doctor-judge, the educator-judge, the social worker-judge; it is on them that the universal reign of the normative is based; and each individual, wherever he may find himself, subjects to it his body, his gestures, his behaviour, his aptitudes, his achievements (Foucault, quoted in Owen, 1994, p.181).

If such power to influence the behavioural responses or conduct of the general populace rests with major institutions - such as the media (and/or the medical profession, the law and others), then how then does the media present material that influences public opinion in such a fashion?

The methods of the media

The public acceptance or rejection of media reporting on a given phenomenon, such as parental resistance to medical advice is influenced by whom and by which means an issue is reported (Lupton, 1994b). In mainstream media, the tendency is to relate events in a style that presents the 'expert' position (law, medicine, or academia) as 'the opinion' by which other opinions are to be measured (or found wanting). What is popularly perceived to be authoritative truth in media is often supplied by experts in the field that the media selects to deliver an opinion that is often no more than a 'sound bite' or a significantly edited excerpt of a longer response (which Bourdieu, 1998b, calls "cultural fast-food"). Thus, the general public's understanding of complicated health related events is closely related to what the media tells them and by those media selected to do the telling. As Lupton (1995) notes: "People tend to rely on media accounts of medicine and public health to construct their knowledges when they have little personal experience of the issue or event" (p.501). Nevertheless, even when supplied with such accounts, the public do not always fully comprehend how the media construct representations of

what is and is not socially acceptable in significant societal issues.⁵⁷ Then again, neither do public audiences always passively accept whatever the media presents (Fairclough, 1992, 1995). At face value, some will reject certain media representations of an issue, others will accept them, and yet others will remain largely indifferent. Public acceptance or rejection, uncertainty, indifference or resistance to media representations of complicated issues is in itself an expected societal norm. In any issue that contains conceptual or technical difficulty requiring considerable reflection that is either lost or misunderstood by the audience; there is a danger of what was extraordinary becoming ordinary, i.e. just another media product amongst millions of others that compete for our attention. Such homogeneity of media messages may therefore not only lead to public apathy towards anything deemed as too difficult to understand, but also to the danger of widespread acceptance of the given cultural message that arrives with the media event. The wider acceptance or rejection of media discourses is therefore dependent upon the ways in which these discourses are framed to shape interpretations of the facts or the 'truth' which therefore influences in turn public responsiveness to public issues such as parental resistance to medical treatments.

Media 'framing' of cases of parental resistance

Irrespective of the continuing debates about the degree of impact that the media has on public opinion (and the problem that public opinion is probably impossible to gauge beyond a certain level), some statements linking the media and its influence on public awareness and opinion remain appropriate within this thesis. As Cheek (2000) notes: "One group of texts that have been very influential in framing the parameters for discussion of contemporary health issues, and even to some extent determining what is a health issue in the first place, is the publications of articles in the mass media" (p. 43). Furthermore, individuals *are* socially located and gain their beliefs about health and illness from the discourses and constructions that are available to them, including media discourses (Chapman & Lupton, 1994); media representations of health, illness and disease produce and reproduce meaning concerning health and illness for lay people and professionals alike (Good, 1994; Seale, 1995); and media representations mediate individuals' lived experiences (Lyons, 2000).⁵⁸ It follows that the media has considerable

⁵⁷ Public opinion research shows (with a few exceptions), that the commercial mass media has contributed little in improving public understanding of either the science or the politics involved in significant societal controversies (Nisbit, Scheufele, Shanahan & Brossard, 2006).

⁵⁸ Within the media, meaning making is socially constructed through institutions, including television networks, publishing houses and newspapers chains (Hoenisch, 2005). Yet, in their constructions, media implies meaning that is neither highly individually owned nor thoroughly examined for representative accuracy before it floods out into the mainstream. Thus, there is little room for any individual acting alone to project their own meaning into the media. In resistance to medical directives, discursive marginalization of parental resistance of all forms is therefore quite likely.

influence in the shaping or guiding of public opinion on matters relating to health, medicine and parental decision making, especially in those situations where there is not only considerable human interest, but also a high degree of controversy.⁵⁹

Those situations involving radical parental resistance that catch the public's eye are nearly always firstly 'framed' by the media, and parents who resist medical advice in regard to their child's treatment are cast by the media in a largely negative light. Their resistance is often seen as a deviation from the norm, against (sound) medical advice, social workers, the law and society itself, at the expense of the survival of their own child. When parents were portrayed differently (i.e. when conforming to medical desires on behalf of their child), they are often framed with their child as brave and/or heroic figures (Lupton, 1994b). Subsequently, the media portrays resisting parents quite differently to conforming ones. In the five cases under review, for example, the initial framing of cases parental resistance in headlines is often dramatic and suggestive of abnormal behaviours (see Figure 1, over page).

Parents who resist medical advice disrupt taken-for-granted routinised practices that occur within the medical setting *and* within the legal system. This disruption is therefore unwelcomed and puzzling for doctors who, faced by challenges to the limits of their own medical field (i.e. those sets of historical settlements that exist between parents and physicians about the 'normal' treatment of a seriously ill child), are exposed to a situation that they find inexplicable or disturbing. Such exposure is unwelcome because it challenges not only medical and legal habitus, but the medical and legal fields as well (Bourdieu, 1977a, 1984). To disrupt both is akin to disrupting the hidden mechanisms of two of the most established norms or even the utopian ideals of society, namely the 'rightness' of medicine and law, and in doing so, medicine and law identify, define and enforce societal norms. As Foucault (talking here of those deviants who occupy a 'heterotopia'⁶⁰) maintains:

...heterotopias of crisis are ...being replaced, I believe, by what we might call heterotopias of deviation: those [sites] in which individuals whose behaviour is deviant in relation to the required mean or norm are placed (Foucault, 1984a).

Parental behaviour that steps outside the norm and into a type of heteropia is therefore 'problematized' or made into an example of unacceptable difference by means such as labelling, normalising and appeals to governance (Foucault, 1991, 1994). The media plays its part in the

⁵⁹ Four of the five 'radical' cases (i.e. Liam Williams Holloway, 1999-2000; Tovia Laufau, 1999-2000; Caleb Moorhead, 2001-2002 and Caleb Tribble, 2003-2005) selected for analysis in this thesis offer examples of media driven attempts to shape public opinion.

⁶⁰ Foucault (1967/1984) saw heterotopias as places that exist probably in every culture and in every civilization which are something like counter-sites, where all the other real sites that can be found within the culture are simultaneously represented, contested, and inverted.

positioning of such parents through the use of mechanisms that firstly show how such parents are different from parents who conform, and secondly to illustrate their deviancy via means of constant comparison with the socio-cultural norms that exist between parents and physicians within medical settings. For example, in the television transcript of the Tribble case (see Figure Two, over page), normal and abnormal behaviours are presented in a variety of ways. The child was a ‘normal’ at birth – he “weighed a healthy 4.8 kilograms”, but (ab)normally was not taken to a doctor when ill; the parents were not ‘normal parents’ – they “chose a life of isolation” and “kept themselves to themselves”; and in a largely secular society, “believed that God would provide”. The child had a kidney infection that was a relatively “straight forward” one to treat, but the parents had (against the norm) chosen prayer instead of medicine; and the father himself confessed that he and his wife had not ‘conformed’ and were therefore liable to criticism and judgement (by the rest of society).

- ‘Parents dice with boy’s life’ (12 February, 1999).
- ‘Parents put boy's cancer into hands of god’ (12 October, 1999).
- ‘Parents beg to be left alone’ (13 February, 1999).
- ‘Liam case worried Mangare boy carers’ (15 October, 1999).
- ‘Doctors told to get tough on parents’ (17 October, 1999).
- ‘Cancer-stricken boy tried to jump from car’ (22 August, 2000).
- ‘Parents' agony over son they loved to death’ (25 August, 2000).
- ‘Use courts to hit lagging parents’ (26 August, 2000).
- ‘Parents face trial for manslaughter of 7 month old son’ (27 November, 2001).
- ‘Science, religion and a dying baby’ (6 June, 2002).
- ‘Measured response best way to help other children at risk’ (18 June, 2002).
- ‘Police probe death of ‘healed baby’’ (11 December, 2003).
- ‘Family thought baby was healed’ (15 December, 2003).
- ‘Parents in court for failing to provide necessities of life (23 March, 2004).
- ‘Dead baby’s parents charged’ (27 February, 2004).
- ‘Family prayed to revive dead baby’ (18 December, 2004).
- ‘Jury struggles with Tribbles decision’ (18 November, 2005).
- ‘Tribble baby death not manslaughter’ (18 November, 2005).

Figure 1: A selection of newspaper/web-based headlines concerning parental resistance, 1999–2005.

Media representations of parental resistance

Parents who resist medical advice or practices are not usually represented in the media as being supportive of societal norms such as seeking medical help for a sick child, and therefore they are rarely seen as being entirely worthy of public empathy, nor are they portrayed as willing or reliable followers of the normal conventions of society (Fowler, 1991; Lupton, 1999). Figure 2 is an example of recent media representation of a case of parental resistance (*italics added*):

Caleb Tribble was born on August 8 2003; he was the youngest of eight and weighed a healthy 4.8 kilograms. David and Catherine Tribble chose *a life of isolation* in a remote Northland valley, 60 kilometres northwest of Whangarei.

Devout Christians *they keep themselves to themselves*, want for little and *believe God will provide*. In the spring of 2003 their faith was tested to the limit. The family had all had a gastric illness.

Caleb was also ill - he suffered weight loss, vomiting and diarrhoea, but his parents thought he was starting to recover, and put that recovery down to God answering their prayers. "If I'd have known what we know now - which is hindsight, a wonderful thing - then he'd have gone to the doctor," says David/Catherine.

But Caleb didn't go to the doctor and unbeknown to the Tribbles he had a kidney infection. Doctor William Wong from Starship Children's Hospital says urinary infections can be quite difficult to diagnose, particularly in infants who are not toilet trained.

"They may exhibit very non-specific, vague symptoms of not feeding, perhaps a fever, sometimes weight loss... so it can be very, very difficult to diagnose," says Wong. He says it is relatively straight forward to treat once diagnosis has been made.

A public health nurse had visited the Tribbles several times during Caleb's brief life. But when she saw Caleb the morning before he died, she said she urged the Tribbles to seek help.

The Tribbles say she never told them to take Caleb to a doctor, but that they were considering it. They instead turned to David's father John to lead them in prayer for Caleb's recovery. But the urinary infection had caused blood poisoning and Caleb died.

Those actions formed the basis of the trial and raised the question of whether the Tribbles had neglected their baby by not taking him to a doctor. How critical the jury would be of their religious beliefs was also a key factor.

"*Unless you conform you always open yourself up to that sort of judgement by people*. Doesn't matter whether you're Christian or a Muslim or a Hindu or a Buddhist or whatever you are. You put yourself up as a mark for criticism, for judgement.

Whether it's in ignorance or whatever... it's just the way people are," says David. The Tribbles believed the power of prayer was, at the time, enough and that it is easy - in hindsight - to say they should have done more for Caleb...

Figure 2: An edited transcript from the television presentation 'The Tribble Case'; *italics added* (Christie, 2005).

The media seem to be covertly responding to the 'problem' of parental inability to following 'acceptable' behavioural rules (or social regulation) when faced with a health related crisis involving their own child. Such rejection of both a positive public image and commendable behavioural traits (in the face of adversity) leaves the parents belonging to the symbolic or archetypal category of 'deviant.' Hence, whatever archetype (i.e. 'culturally different', 'misguided' or 'ignorant') is allocated by media to resisting parents, none are particularly complementary, and all suggest nonconformity through 'otherness.' On examination of media reporting in cases of *radical* parental resistance, these categories tend to

follow a distinct pattern or ‘spectrum of deviancy’ where resisting parents are perceived in single or in mixed multiples of categories as culturally different, or deeply religious, or simply misguided, through to malicious or blindingly ignorant.

Parents as ‘culturally different’

One discursive theme that predominates in the discourses surrounding parental resistance to medical treatment is that of the parents as simple or modest folk of a minority ethnic background who sought medical help but eventually rejected it in favour of alternative solutions. This was overtly the case in the Laufau and Baby L cases, because those parents were identified as being of Pacific Island origin. To an extent, the parents in the Moorhead and Tribble cases were covertly identified as culturally different because they were members of small religious groups or ‘sects’. Only the Williams-Holloways were seen as more ‘middle-of-the-road’, and they did not attract the ‘culturally different’ label in the same way. Often, the ‘culturally different’ archetype is related to notions of cultural inferiority or simplicity as opposed to cultural superiority; these are differences in cultural capital (Bourdieu, 1984). As such because difference “...refers to a culturally-specific ‘competence,’ albeit one which is efficacious—as a ‘resource’ or a ‘power’—in a particular social setting” (Weininger, 2005, p. 122), the implication is more likely to be a negative one when one culture is seen to hold a lesser degree of cultural capital.

The Laufau case illustrates this archetype well, where the media reported the case by appealing to the notion that the Laufau’s cultural belief system was naïve, their social setting alien, and therefore (by implication) their cultural capital was an inferior resource. For instance, the media planted the idea that the parents were from a less sophisticated cultural background with the publication of the defendants’ names and place of residence, “*Laufau*, aged 41, and her husband *Peni Laufau*, 52, *both of Mangere*, are accused of...” (“Cancer-stricken boy tried to jump from car: mother”, 2000) which for many readers in New Zealand, carries with it certain preconceived ideas of foreign culture and/or poor and uneducated immigrants (Laufau is a Polynesian name; Mangere is a mainly working class suburb of in Auckland, the ‘largest Polynesian city in the world.’). The media also interviewed and chose to report the comments of an educational ‘expert’ (“Mr. Hodge”) who did not share the Laufau’s cultural background, and was instead the Principal of Tovia’s school:

Mr Hodge said he believed the parents would be confused that police were investigating them. “They’ll be wondering what the heck the European system is doing to them” (Wall, 1999).

Such ideas, i.e. the Laufau’s as culturally simple folk left wondering what the ‘European system’ was doing to them, were eventually reinforced by the media as they reported the later trial proceedings, this time by relating the contributions of another ‘expert’, Doctor Watson:

Dr Watson said the medical world was full of jargon. It was critical for families to understand exactly what was being said at stressful times when bad news about complex issues was being

given, especially when it was in a foreign language and in a "foreign" environment ("Specialist blasts system failures in cancer boy case", 2000, p.A4).

The implication was that the parents did not understand the 'ways of the western world' as exemplified by modern life and modern medicine in New Zealand. To emphasize these points, and to provide a normative standpoint from which the general public should interpret the case, two authoritative figures, a school principal and a doctor were used by the media. Even such basic 'facts' imply subtle, yet cultural and therefore critical overtones within a country where the predominant culture is white, 'middle class' and largely dominant. Such differences in capital, class and field may also draw a degree of public support, in ways reflective of recognition of at least some qualities common to all cultural groups. Hence, perhaps because of the parents' 'cultural naivety', public support came from a number of diverse sources that were duly recorded in the press. For instance:

Principal David Hodge said the death had upset many pupils at the school, about 50 of whom attended his funeral. A Samoan minister held a memorial service at the school. Mr Hodge said he knew the parents well and had "tremendous respect" for them and the children they had raised (Wall, 1999).

Ideas about naivety extended to another major sub-cultural theme of parental resistance, which was parents being either 'deeply religious' or sometimes possessing 'religious fundamentalism', a theme that was exemplified strongly in the reporting of the Tovia Laufau case (as well as in the Moorhead and Tribble cases):

"They are very, very religious. If there was a concern that they did not seek enough medical help it would purely have been (because of) an absolute conviction that God was looking after them. You really need to understand the belief and sense of belief in that family...to really appreciate the situation" (Wall, 1999, quoting Principal Hodge).

A sub-theme, the degree of religious adherence (and therefore acceptance or rejection of modern medicine) was also a feature of the Laufau case (*italics added*):

The Laufau's were devout Christians who believed God was watching over their family. They constantly prayed, with members from their church, for Tovia to be healed. *But their religion did not bar them from seeking medical help* (Larkin, 2000).

These media discourses paint a picture of devoutly religious parents who sought medical help but eventually rejected it for other reasons while still relying on some form of divine intervention. The Laufau case has some similarities to the 'Baby L' case, previously noted, which involved a different form of parental resistance that was against medical wishes to *cease* the medical treatment of a baby rather than continue with it. The parents of Baby L were Pacific Islanders who were "strong in their Mormon faith" (Harder, 2002, p. 245); the baby was buried at Mangare cemetery, and the lawyer paid with "a great big box of corned beef, a mat and a \$50 bill because that was all that the parents could afford" (p.248). As in the Laufau case, some support for the parents' stance was forthcoming, although in this case, mainly from organised bodies of individuals, such as the Assembly of People with Disabilities, a spokesman/bioethicist for the Catholic Church, and the leader of the Christian Heritage Party (Harder, 2002).

Parents as misguided and/or misinformed individuals

Another theme in the media discourses surrounding parental resistance to medical treatment is that of the parents as honourable, intelligent but not particularly 'deeply religious' individuals who initially sought medical help for their sick child but eventually rejected it in favour of alternative solutions, as occurred in the Williams-Holloway case. In this instance, the parents were described as all of the above but still seen as misguided. The media matched the noble, well intentioned but less well informed parents against equally noble and well intentioned - but also 'better informed' physicians. Physicians are thought hold superior knowledges to lay people because they belong to a profession that possesses a great deal of cultural and symbolic capital (Bourdieu, 1984), and because the doctor's focus on disease and facilitation of a cure takes precedence over the relational aspects of the doctor/patient encounter. In fact, as Foucault (1975) claimed, physicians are thought to possess a 'medical gaze'; that is, they have the ability to penetrate illusion and see through to the underlying reality, and in doing so, they objectify disease but subjectify the patient. In short, the physician has the power to 'see the hidden truth' (Foucault, 1975). To achieve this binary position, i.e. to draw out the subjective 'otherness' of the parents and the reliability of the physician's objective viewpoint, the press utilised several 'specialist' sources to offer an opinion:

Liam's parents should be encouraged most strongly to return their son to hospital, he [a specialist] said. [Another specialist] a cancer treatment expert, Dr Vernon Harvey, said halting a chemotherapy course could cause the cancer to become resistant to a second round of treatment (Cleave, 1999).

As media selected specialists maintained, if the parents wanted to use alternative or 'more natural therapies', then they should be allowed to do so, but only in a fashion that was acceptable to the medical profession. In a sense, the parents' desire for alternative treatment for their child was seen by the media as an obstacle to be overcome rather than a possible part of the treatment. To achieve this, and to show that even the parents' odd (i.e. not mainstream, not rational) ideas about alternative treatment were acceptable up to a point, the position of some alternative therapists was ascertained and used in conjunction with the medical position:

The national organisation which registers natural health practitioners urged the person treating Liam to make himself or herself known. "The two professions [medical and natural] need to be working together," said Paddy Fahy, chief executive of the Charter of Health Practitioners. He said Liam's parents could have consulted any number of natural healers and tried anything from herbal remedies to electromagnetic therapy (Cleave, 1999).

Early on in the case, the parents were clearly represented as being resistant to (sound) advice from all those authorities on child cancer and its possible (medically established or alternatively respectable) treatments.

Subsequently, and quite quickly, the consulting physician acted to retrieve the child for further treatment. The child was to be made a ward of court as soon as the fleeing family was found, and the public were asked to act as lookouts for the police. Thus, in the eyes of the media (which reflected medical and legal opinion) and the parents' actions went against the norm, and

represented a case of misguided parents fighting 'the system' for no particularly good reason. Yet, as it transpired, the parents did not resist in ways that offended the public's expectations. In fact, the parents were given considerable public support; they were also well supported by others who possessed considerable cultural capital both within and without their immediate circle:

Patients' and children's advocates yesterday intervened in the case of missing 3-year-old cancer patient Liam Williams-Holloway. They offered to help his family seek a judicial rethink. The Health and Disability Commissioner, Robyn Stent, said it would be irresponsible of authorities to assume the state knew better than the child's fugitive parents and to rule out alternative treatments to chemotherapy. She challenged the Children, Young Persons and Their Families Agency to work with Liam's parents, Brendan Holloway and Trena Williams, to decide what was best for the boy and not ignore alternative therapies. Both Robyn Stent and the office of the Commissioner for Children offered to mediate to persuade the couple to put the case for alternatives to the Family Court, which has authorised Healthcare Otago to continue chemotherapy (Dearnaley, 2000).

This viewpoint, from a national figure such as the Health and Disability Commissioner seemed to mark a change of mood for both press and public alike. It reinforced the arguments of the family's spokesperson, an equally articulate woman who frequently provided a reasoned position via her contact with the press:

A family friend in Liam's home district of Wanaka, Jude Battson, last night said Robyn Stent's [the Health & Disability Commissioner] intervention was terrific, but she believed the parents would be wary of any offer of mediation by a state agency (Dearnaley, 2000).

And so, arguably, began the theme of the 'noble' parents against the odds, which was reinforced when the father came out of hiding to announce:

"People say if our son dies, we are killing him. We want people to accept that the alternative medicine measures we have taken are what we believe will help Liam. We don't believe conventional medicine was working." He said he wanted the public to understand their decision... ("Liam's parents tell of faith healers", 1999).

For quite some time, Liam's parents were seen by some to be 'outlaws' and by others as archetypal 'resistant fighters' for choice. As more people showed support for the parents, and the media were held accountable by a court imposed media ban⁶¹, the tide turned further in the parents' favour as even the previously cautious alternative health therapists representatives 'went public':

The hunt for 3-year-old cancer sufferer Liam Williams-Holloway will deter parents from sending other sick children to hospital, say natural therapists. A spokesman for the Charter of Health Practitioners, Kenneth McIver, said last night that he feared a backlash over Liam's case was already making parents scared to seek medical assessments for their children ("Parents fearful say healers", 1999).

The overall effect of such statements was to lend more support to the parents' actions, which gradually became a vocal public movement:

⁶¹ At which point the case also became about the freedom of the press; i.e. the role and rights of the media itself became the story.

In a message read to hundreds of supporters gathered at candlelight vigils round the country last night, the parents of cancer sufferer Liam Williams-Holloway said he was happy and healthy and making good progress. The demonstrations were held to offer support to the family, make a stand for the right to choose which type of health care is used and to oppose the media ban imposed on coverage of the case (Burge, 1999).

In essence, the resistance was spreading rather than failing, with the family's plight becoming a rallying point for the public rather than (as noted in previous discussion) a point of separation or 'marginalisation'. It is speculative to argue that the groundswell of public opinion changed the stance of the medical position, but before long a 'deal' was attempted:

Dr Sullivan said that under a deal with the parents, HealthCare Otago agreed to drop the legal action to make Liam a ward of state if they returned Liam to hospital for tests. But last night family friend Jude Battson said this was unlikely to happen as the family intended to continue alternative treatment. "They were never intending to return to the doctor", she said. "They are going to remain with the alternative treatment, which they are happy with" (Perry & Sell, 1999).

In the end, the parents took Liam abroad to a Mexican clinic for alternative treatment, and later to a German hospital for conventional treatment. Liam eventually died from his illness and gradually, with an occasional glance back to Liam and his parents, the media moved on to the next case. Medical 'diffidence' did not remain for too long, although it is thought to have affected the outcome in Tovia Laufau's case (as doctors in that case did not pursue a court order for treatment; see earlier discussion). Following Liam's death, an article appeared in the press that finally seemed to understand that the media's commonly used (and binary) approach – the established versus the alternative, the learned versus the ignorant, and the power of the state versus the power of ordinary people – was in itself a misguided simplicity in this case, and media reporting became more balanced:

His case has had a profound effect on the country, raising intense debate about the propriety of his parents' decision and the powers of the state to overrule the rights of parents when a child's life is at stake. The medical and welfare authorities were plainly taken aback by the divided public response to their appeal for help to find the child. They have been most diffident in using their powers since then, perhaps too diffident (Editorial: "Little boy's death leaves last lesson", 2000).

The Tribble case has some similarities to the Williams-Holloway case in that the parents were not adverse to seeking medical advice, and they were eventually treated quite lightly by the law. However, there were strong religious overtones in the Tribble case, and as may be expected, occasional references were made to similarities between the Tribbles and the Moorheads (i.e. both lived in isolation from the community, both were 'deeply religious' families, both used prayer to heal a sick child). However, such attempts to link the two families through fundamentalist religious belief systems were eventually brushed aside, particularly by the Tribble's lawyer, who went to some lengths to distance his clients from any similarities with the Moorheads (see further discussion in Chapter Five).

Parents as ignorant and/or malicious

When the 'Moorhead case' first came to the public's attention, one newspaper headline ran as follows: "Accused told police of 'Satan's way'" (2002), which immediately suggests that the

article was about someone who holds strong religious beliefs. Although the holders of fervent religious beliefs may be seen as an anachronism in New Zealand society, often being represented in the media as either traditionalists within a minority group or as a quaint subculture within society⁶², New Zealanders themselves are usually portrayed as tolerant and enlightened:

New Zealand is a liberal, tolerant and secular society, a society that embraces the Western Enlightenment ideals of personal liberty, private property and rationality as the basis of decision-making. These are values so central to our society that we hardly even think about them (Brash, 2006).

Yet, regardless of the reference to a liberal, tolerant and secular society, there are times when some people are set apart from 'ordinary New Zealanders' because of their apparent belief systems. As such, they are not only 'marginalised' but also run the risk of being labelled as 'strange' or 'suspicious' or 'deviant.' Such marginalisation is an example of historical biases (such as the fear of cults or secret societies) namely a deep suspicion of those who sit outside societal norms, and are perceived to be 'detached' or 'different' or even 'resistant' in one form or another (Foucault, 1980a).

The Moorhead case, unlike the Laufau case, was represented in the media from the beginning as a case highlighted by religious differences from the majority of society, and initially framed by the use of religious symbolism. For instance, the media reported the dead child's father's comment to the police that conventional medicine was "Satan's way", and also reported that: "They each carry a Bible into court" ("Accused told police of 'Satan's way'", 2002). The exposition of the parents' religious views continued in the same press report with clear reference to the religious nature of the Moorhead's resistance towards medical help for their child:

Moorhead, a Seventh Day Adventist, said that if he was faithful to God "when Jesus comes again I will get time with Caleb again"....He said there was a war between Satan and Jesus...Mr Dudley asked Moorhead if he was saying that Satan's way would be to seek conventional medicine and that God's way was the other way? Moorhead replied that he was ("Accused told police of 'Satan's way'", 2002).

The link is therefore quite explicit: The Moorhead's held strict and 'fundamentalist' religious views that led them to reject medical advice. They were not like 'ordinary New Zealanders' in that they believed in the devil, carried Bibles into Court, and refused to be legally represented. This sense of 'otherness' (of their religious beliefs) was represented by media as an immovable force that overcame any other force, which in their case, included medical and legal power. As

⁶² It is worthy of note that in some western countries, such as the USA, there remains "a high level of religiosity" (Seale, 2001, p. 426). Contrarily, New Zealand has low levels of religious beliefs; in fact, it has been described as one of the most secular societies in the world (Geering, 2005).

such, the media presented the 'facts' about the Moorhead's relationship with physicians in a tried and tested binary fashion, i.e. reason versus unreason, noting that "...their faith overwhelmed any belief in the doctors" (Carter, Stickley, Inglis, & Laxon, 2002, p.A9). It did not take long after the Court case began for investigative reports to probe into the Moorhead's once private life and affairs, and to draw conclusions about the nature of their religious beliefs which were then presented in largely negative terms. Mr. Moorhead was presented as a man who was once seemingly 'normal' by conventional New Zealand based standards, but was later 'turned into a different (the implication being 'worse') man':

Not so many years ago Jan Moorhead was a successful, hardworking man with a big house and a swimming pool in rural Dargaville. Like many Kiwi blokes, the earth working contractor lived on a diet at dinner time of meat and three vegetables. Then he left his wife and two children and moved in with Deborah Murray. His ex-wife, Deborah Downey, says her husband of 15 years turned into a different man. From a workaholic, bulldozing expert who liked to say "religion is for suckers", he became a deeply religious vegan. He cut his hair short and ate only the fruit and vegetables the couple grew. Breakfast was porridge with nuts and mealtimes were at 9am and 3pm only. For Downey, the most hurtful thing was the way Jan's new wife tried to turn her daughters - now 13 and 14 - against her, telling them that her mother was evil. "Everything was to do with Satan," she says. "For the girls it was quite upsetting." They weren't allowed to play and had to have Bible lessons. They had to eat the food and they hated it" (Carter et al., 2002, p.A9).

The above media transcript reveals an element not seen previously – the husband was once a 'normal Kiwi bloke' but was changed by his hypocritical new wife, who by all accounts, tempted him to commit adultery but was also responsible for his dramatic religious conversion. In many ways, this notion dwells upon a sinister theme that is perhaps as old as Adam and Eve, namely an ordinary decent man is brought down by a devious woman. In any event, Jan Moorhead's conversion was for the worst according to other family members and clearly, the press, because the Moorheads became 'fringe dwellers' in a religious (if not a physical and material) sense: "They were part of a radical fringe of the Dargaville Seventh-Day Adventist Church" ("Ordinary man's faith cost a life", 2002). The connection to a fringe religion once established, it was not too difficult to make the connection more overt by using a reliable (to be read as authoritarian) source in the form of a police detective sergeant:

...."My feeling is that these religious beliefs have blinded them to the realities of the situation they were in. Their strong religious beliefs coupled with their very strict vegan diet - that combination certainly produced the situation that they find themselves in" ("Ordinary man's faith cost a life", 2002).

The authoritarian sources employed by the press in the Moorhead case grew as the case went on, and included state actors, and those representing the medical and legal professions, culminating in the couple's actions being rejected even by leading figures within their own (wider) church:

Immediately after yesterday's verdict, the Seventh-Day Adventist Church moved to distance itself from what the Moorheads did..."These people are certainly following a lifestyle not in harmony with the mainstream Christian church. That's probably the easiest way of me saying it: they're not part of our mainstream church," said the North New Zealand conference president, Pastor Jerry Matthews ("Ordinary man's faith cost a life", 2002).

The Moorhead's had become "these people", "not part of the mainstream church", considered as being both extreme and unusual. Subsequently the press hunted down the presumed origins of the Moorhead's religious beliefs, promptly labelling that source as the cause of their infant's death. The *New Zealand Herald* used the heading: 'Prophet's message cost baby his life', and offered the following:

The religious group at the centre of the Caleb Moorhead case follows the teachings of a 19th century prophet who advocated natural healing and a strict vegan diet. The dozen members of the White Horse Ministry do not smoke, drink or take drugs and do not own televisions or believe in unisex clothes. They follow the beliefs of Seventh - day Adventist prophet Ellen White. Their first headquarters was the Dargaville home of Sheryl Jensen, a grey-haired 55-year-old, who outlined her beliefs in an exclusive interview with the Herald yesterday. She follows a strict regime of eating twice a day and drinking water one hour before and two hours after each meal. She refuses prescribed medicines, instead relying on natural remedies, and prays often (Carter, 2002).

Even vegetarians shrank at the association with the Moorhead's lifestyle and the case, and the Moorhead's alienation was therefore complete:

Vegan Society co-ordinator Sandra Murray was worried vegans would be marginalised after Caleb's death and wanted more nutritional information available for vegetarians and vegans (Carter, 2002a, p.A1).

In an article that quickly followed the jailing of the Moorhead parents (they received a five year prison sentence), the final media based coup-de-grace on the actions of the Moorheads, and by default, on any individuals who may hold religious values that shun modern society and its medicine, was delivered:

When it comes to depressing idiocy, nothing that happened so far this year - or most other years - can beat the Moorhead case. This couple from Dargaville used fanatical religious beliefs as an excuse to allow their 6-month-old baby to die a horrible, but apparently spiritually correct, death (Witchel, 2002).

In this, it can be seen that the once 'deeply religious couple' were now people who held 'fanatical religious beliefs', and that their infant's death was both 'horrible' yet 'spiritually correct'. The reporter goes on to describe the Moorhead's religious beliefs as those of "some lunatic fringe." Such use of irony is perhaps understandable in an article full of vehement outrage about the apparently unnecessary death of a child, but its outrage ran close to condemning all parents who belong to minority religious groups or sects that rely on themselves rather than conventional medicine/the state/the 'societal norm' for help when their children are unwell. Indeed, the writer goes on to claim: "No beliefs, religious or other, should be tolerated if they deny any child adequate medical care" (Witchel, 2002). This media homily was clearly meant to represent individual outrage, but it also goes further by attacking not only the Moorheads but any others who choose to hold alternative religious beliefs, or seek out alternative treatments for their children. In this way, a link is made between simple, fundamental and often 'minority religious beliefs' and ignorance and irrationality, and also between medicine, law and basic common sense:

But in the face of deliberate, determined ignorance of this calibre, there's no guarantee anything could have been done. We're dealing here with superstitious thinking that predates laws, medicine and basic common sense. To ensure their spiritual purity, these parents were willing to sacrifice

their child...Surely this was a bizarre and isolated case, I thought. Then I went on the internet. You could be there for days, weeping over stories of innocent children dying agonising and pointless deaths while their parents prayed (www.childrenshealthcare.org is a harrowing place to start) (Witchel, 2002).

In short, the Moorhead's were not just fervently religious, they were ignorant and malicious; they not only spurned the rest of society, but sound and considered medical assistance, thereby implying a medieval mentality (i.e. one that belongs in the dark ages rather than in the twenty-first century).

Doctors as proper representatives of medical treatment

Lupton (1994b) maintains that in the popular mass media, representations of medicine, illness and death are a matter of routine, and furthermore that:

Previously published research has suggested that biomedicine and members of the medical profession tend to be portrayed far more positively than negatively in the mass media (Lupton, 1995, p. 507).

Indeed, the media are enthusiastic in the reporting of medical breakthroughs, personalised stories of recovery from dangerous, life threatening illnesses, and stories of the death of a famous person or the dramatic death of an 'ordinary' person (Lupton & Mclean, 1998). Representations of medicine and medical personnel tend to reflect the altruistic and dedicated side of medicine.⁶³ Doctors are generally portrayed as "omnipotent figures that have the power to save lives against the odds" (Lupton, 1994a, p. 53), and those who seek to offer alternatives to the sound advice of physicians as being suspicious, and even as quacks, an old term for those who sought to enter the field of medicine without the 'right qualifications.' Such a clear (binary) split between the publicly sanctioned members of the medical profession and the would-be usurpers of this role which included "charlatans, quacks, and 'unqualified and incapable persons practicing medicine'" (Foucault, 1975, p. 52) is a well recognised phenomenon going back to the Age of Enlightenment. From that time great efforts have been made by members of the medical fraternity to limit the entry into the medical profession through the requirements of the acquisition of a body of knowledge (based on the 'episteme of the Enlightenment') obtained within a formal education. Such requirements have gradually increased the cultural capital of medicine whilst gradually decreasing the cultural capital of 'alternative' practitioners.⁶⁴

⁶³ This does not mean that there are no alternative presentations of members of the medical profession. Indeed, it is argued that a trend to show physicians in a less than glowing fashion has been emerging in media over the past few years (Lupton, 1995; 1998).

⁶⁴ I.e. 'alternative practitioners' who were once part of the 'mainstream' but fell out of favour when modern medical methods became the norm. For further discussion, see Chapter Seven.

In cases of cancer, the role of the physician as the altruistic miracle performer who holds the key to survival generally prevails, and the doctor's ability to 'call the odds' is a frequent and popular event in media reports concerning cancer and children:

An Auckland children's cancer specialist, Dr Scott MacFarlane, said the chances of children surviving the cancer ranged from 90 per cent to less than 10 per cent in its most advanced stage (Cleave, 1999).

These predictions, which are part of the use of medical technology described by Lupton (1994a) as "the apotheosis of medical magic" (p.53), are part of the trappings of medicine that are for many a source of fascination and awe. So it is no particular surprise to find that the medical mores associated with modern cancer therapies – fighting courageously against heavy odds, the all-knowing physician, the kindly nurses, the magical technology and the added drama, have a 'place of honour' in the popular media.

Such drama can therefore only be magnified when the case involves a child (who is always portrayed as an innocent victim and deserving of medical treatment – as opposed to a sixty year old smoker with lung cancer) when 'life and death' is at stake, and when there is a chance to show modern medicine performing miracles. However, in the cases described already in this chapter, a key spoiler is nearly always resisting parents, who, in ordinary circumstances, are not a central focus for the heroic discourse at all (Seale, 2001). Even worse, when those parents seem to choose alternative therapies over the traditional, then the discourse becomes not just a standard support for the marvels of modern medicine, but an attack against any or all who would seek to offer a different option or response to established treatments:

New Zealand children who have been treated at cancer clinics in Mexico have never been cured - and many have died, says a top child cancer specialist. Several dozen clinics in Mexico offer a range of alternative cancer treatments... Dr Lochie Teague, the head of the Starship children's hospital haematology and oncology unit, said yesterday that the clinics were expensive rip-offs preying on desperate people and offering false hope (Masters, 1999).

In the above excerpt, a medical authority, i.e. "a top child cancer specialist", is used to illustrate the suspicion that underlies any possible alternative to the medical norm. Not only are the Mexican clinics seen as ineffective, but also money making fakes who offer 'false hope' and may be using a form of medical intervention that is, or was, an affront to established medicine. This discourse is a constant theme in media reporting of illness, medicine and/or death. Furthermore, if any alternative therapy was shown to be effective, then it would be a part of established therapy – 'returned' to the fold, as it were. By implication (i.e. as a more covert discourse), the parents that are taking their child to such a clinic are clearly misguided and heading into a dubious and risky arena.

Alternative therapists as 'quacks'

As previously maintained, the increase in the social status of the physician/surgeon from the era of the Enlightenment meant an increase in the social and financial rewards associated with becoming a medical professional. Such a membership brought with it considerable cultural

capital in the form of status and money (Bourdieu, 1984, Foucault, 1975). Furthermore, the absence of some or any of the key requirements of belonging to a modern profession (which, according to Flexner [1915] included intellectual rigour; the use of science and learning; an educationally communicable technique and self-organization) meant that being outside of this lucrative field left one open to the label "quack" and therefore liable to marginalization by the medical establishment, and through their influence on public opinion and the media, by members of the general public as well. Both the medical profession and the media have pursued certain stereotypes in this regard, for instance:

A common stereotype of the founders of alternative medical systems is that they are "quacks" - basically uneducated and untrained, out for a quick buck, and occupying a 'marginal' place within society. They are thought often to be "cranks" - people who have an axe to grind against the "system" because they could not succeed at it. An examination of the founding figures of most alternative medical systems would show just how incorrect this stereotype actually is. In many cases, alternative medical founders are people whose careers began in the 'mainstream' medicine of their time (Mizrach, 2006).

Yet alternative therapies have become increasingly popular with a growing number of people who are dissatisfied with the more traditional medical approach to the treatment of illness (Lupton, 1994a). Indeed, through the media, alternative therapists now often seek to disassociate themselves from established medicine to emphasize their 'otherness', but do so in ways that either attempt to work alongside modern medicine ('complimentary medicine') or remain apart from it ('alternative medicine') while representing little threat to it. Such differences between medicine and complimentary or alternative medicine (often referred to as 'CAM' - which is another attempt to soften the distinctions between the two approaches) are often at their most critical and obvious when dealing with treatments for cancer.

A typical example of media uncertainty and bias towards alternative therapies occurred during the media interest that ran throughout the Liam Williams-Holloway case, when on several occasions, the media attempted to reflect the growing public debate about alternative treatments for aggressive childhood cancer. In the following extract, the approach was to appear to present a balanced argument on both sides:

Chemotherapy is a stab-in-the-dark treatment which kills healthy cells along with cancerous ones, say alternative health practitioners. As medical doctors urge the parents of Liam Williams-Holloway to return him to hospital to continue chemotherapy, some natural health exponents say that treatment may well kill him. Natural therapies, they say, are kinder - leaving behind the "cut, poison and burn" approach. Sceptics and some in the medical profession question whether alternative healing treatments work, but many natural therapists say there is no proof that chemotherapy works, particularly with cancers such as neuroblastoma, which Liam has. Instead, they recommend a range of therapies to boost the immune system and allow the body to heal itself (Masters, 1999).

Yet such claims often lead to dismissals from both established medicine *and* the media, either in the same article, or sometimes in counter-arguments via the means of 'investigative journalism' that seeks to draw what are perceived as significant distinctions between established (or 'mainstream' medicine) and alternative medicine. In the following extract, the Bowen treatment,

a form of therapeutic massage, is held in the media gaze as being too different from established medicine (and clearly not a recognised profession), and therefore too 'extreme' as a course of action:

Medical students can spend 12 years training to register as a specialist; Bowen therapists' specialist training takes just 12 days. Practising doctors must by law sign up with the Medical Council; Bowen therapists have a voluntary registration body. Errant doctors can be hauled before council re-education and complaints committees, the Health and Disability Commissioner, a court-like medical tribunal and ACC; Bowen therapists, too, can face the commissioner and Bowen Therapy Inc, but there is no independent prosecution body and patients harmed by the treatment have no medical misadventure recourse to ACC, which covers only those health workers who must be registered by law. Admittedly, the scalpels and toxic drugs of Western medical science are capable of inflicting far greater harm than Bowen treatment, a form of gentle touch therapy. But the gulf between the two in training, registration and discipline illustrates the extremes of mainstream and alternative medicine (Johnston, 2003).

The media use of binary cross-references such as 'training', 'registration', in conjunction with the practices of the Medical Council (and being legally registered, and following the ideals of medicine and professionalism) versus alternative medicine (and by implication, non-professionalism) in the above excerpt positions medicine as the established norm and Bowen therapy as the unregulated alternative. In some cases, the media presents stories that indicate that alternative therapists are treated as rank 'outsiders' in ways that maintain their 'marginalised' state and punish them for being so. In this fashion, they are treated by the law at least in ways that mirror past treatments of homosexuals, or healers, or even the present treatment of criminals (Foucault, 1977). For instance, unannounced and often disturbing *police raids* (one immediately thinks of 'drugs busts', or breaking up illegal gambling dens) on the premises of alternative treatment providers still occur:

Police raided the Rainbow Health Clinic on Tuesday, seizing evidence that it had treated the 3-year-old Central Otago boy for several weeks until seven days earlier. They believe he and his parents, Brendan Holloway and Trena Williams, are still in the North Island but refrained from searching any more properties yesterday. Gerard and Dawn Uys, who run the Rainbow clinic, remained too shaken yesterday from the raid to discuss their treatment in detail (Dearnaley, 2000).

It seems very unlikely that such an event would happen in a doctor's clinic where 'gentleman's rules' would apply; i.e. the physician would be politely subpoenaed. Overall, in cases of parental resistance, the media reports and supports the acceptability of traditional medical practices whilst at the same time questioning the suitability of alternative therapies.

Suffering children as innocent heroes ...but resisting parents as unheroic

Medical-psychological discourses about children who are seriously ill, and especially with cancer, frequently concentrate upon the child as psychologically and physically disadvantaged, and therefore prone to problems of social withdrawal, separation anxiety, post-traumatic stress disorders, isolation and dependency (Barakat, Kazak, Gallagher, Meeske & Stuber 2000). However, such children are also represented by the media as ordinary (or even extraordinary) innocents combating a disease that has not prevented them from bravely fighting a 'battle' against the odds (Johnston & Mold, 2000). As such, the typical media archetype of such a child

is either as “being brave or specially courageous” and/or “cheerful and uncomplaining in the face of the terrible ordeal of their illness and treatment” (Dixon-Woods et al, 2003, p. 148). The media therefore ‘glosses over’ any disturbing psychological effects of the illness on the child in preference for a more ‘heroic’ or ‘stoical’ viewpoint.

The media frequently offers separate opinions about parents and child in those cases where parents are not seen as being fully supportive of the child’s brave fight against the odds (with the aid of modern medicine). Parents who do not appear to fulfil this given role in society (i.e. as wise councillors for their children ready to accept and comply with the even wiser council of medical practitioners), are treated by the media in a condemnatory fashion. In the next excerpt, note how the ‘good kid’ image is promoted, but that the parents are misguided by their love for their child. In an article entitled: *Parents’ agony over son they loved to death*, the child is praiseworthy, but the parents are blinded by devotion:

Tovia Laufau was a typical 13-year-old teenager - until March last year. He played video games, watched a lot of television and hung out with his mates and siblings. He loved rugby. A third former at Tamaki College in Glen Innes, Auckland, Tovia was described yesterday by Principal David Hodge as "a delightful boy" who came from a loving, caring family. "He was a lovely kid. Like all the kids in that family - really delightful young people." ...Tovia's parents, Peni and Faafetai Laufau, both Seventh Day Adventists, were devoted to their children and doted on their son, describing him as "a very special young man. Gifted." It was this devotion which killed him (Larkin, 2000).

In the last excerpt, it may be noted that even though the parents were represented as being rather simple folk from another culture, there was some sympathy for their situation. At times, and in response to tales of parental difficulties and child death as a result of it, the media release a type of ‘brave child-parent’ story as a potential means to counterbalance negativity.

Suffering children and their (conforming) parents as heroic figures

As previously maintained, media supports physicians over resisting parents in the popular press. This suggests that the media perceives such issues in a largely binary fashion by making a clear distinction between ‘proper’ responses to social issues, and improper ones (Foucault, 1979). Thus, those parents who flout medical opinion become marginalized, nearly always receiving a less than favourable reception in the media, and in the subsequent public understanding of their actions. However, in a few cases to the contrary, especially where it seems that the media picks up on a public trend that implies greater support for parents than was perhaps anticipated, the media sometimes presents a more favourable or sympathetic reception for resisting parents (as occurred in the Williams-Holloway case). In short, the media appreciates those parents who offer little resistance to the use of medical technology and concur with the medical professional’s treatment advice.

Bourdieu’s (1984) description of the use of symbolic and cultural capital within a given social field is relevant in the media’s portrayal of the ‘proper way to fight against disease’. As noted previously, the media feeds its target audience (i.e. ‘middle’ or ‘mainstream’ New

Zealand) with 'good news' stories about successful medical treatments of serious child illness because the public wants heroes. The media is a "celebrity-making machine" (Calhoun, 2002, p.1) in this regard, and promotes success through personal endeavour. Subsequently, those stories where a child and his/her parents offer grateful praise to the physician/wonder drug/medical system that has saved them feature in the media on frequent occasions (Lupton, 1994b). For instance, in an article entitled: *Teen backs chemotherapy*, the 'proper way' to respond to illness is promoted as one that is noble and heroic, in line with medical wishes, dismissive of any notion that alternative therapies may have a place, reflective of the 'proper' or acceptable role of religious belief systems, *and* reflects well on both parent and child alike:

Thirteen-year-old Aslan Perwick believes faith helped him to survive the cancer that threatened to take his life, but says he never once considered seeking alternative treatments... His mother, Kyra Perwick, attributes her son's survival to conventional treatment, Aslan's strong character, and their spirituality, including a hanky sent by a Wellington Catholic priest who holds healing Masses (Johnston, 2000).

This case, quite unlike Tovia's, represents simple but well placed trust in medicine, with only limited religious overtones of 'mainstream' religion that are largely played down in the text; it exemplifies the socially 'acceptable' response from both child and parent. Indeed, apart from facing a life threatening cancer, everything about Aslan's case seems different, i.e. the boy was so impressed with his doctors that "he now wants to become a cancer specialist", unlike Tovia, who was desperate to flee from medical care of any sort, neither was he given the accolade of being 'of strong character', as in Aslan's case. There are other obvious differences; Aslan lived in *Torbay*, a relatively affluent suburb of Auckland, was of European extraction, and complied with medical directions from the start.

The law as the state sanctioned arbiter of societal behaviour

The language of the legal system is meant to be a 'neutral' one, the facts of the case being regarded as the most important. However, descriptions of cases are not without social impacts, and in reporting verbatim from court proceedings, the media is part of a system that transmits the symbolic language of the judiciary to the public. Such reporting has a greater effect on the public than if it were written by a journalist; powerful messages and meaning are transferred from more authoritative sources than the media, thereby influencing public opinion and behaviour through the media's role as a conduit for relaying disciplinary practices. For instance, in one brief excerpt from a law report, the child is "suffering cancer", the physician is "an agent of the court", a child "has the right not to be deprived of life" and perhaps the most telling phrase, "without intensive chemotherapy [the child's] death will be inevitable" (FP012/23/99 [1999] NZFLR 804). When selectively transferred to the public through the media, legal language is not particularly neutral at all because it provides either direct phrases that may carry significant (symbolic) meaning, or material from which the media develops its own meaning. Hence, taking its lead from the judicial system, the media may become increasingly

judgemental and vitriolic, as in the reporting of the Moorhead case, or increasingly measured and sympathetic, as in the Tribble case (see Figure 3).

Moorhead case	Tribble case
<p>'Parents face trial for manslaughter of 7 month old son (27 November 2001). 'Parents ignored baby's slide towards death' (27 May, 2002) 'Accused told police of "Satan's way" (1 June, 2002) 'Science, religion and a dying baby' (6 June, 2002) 'Prophet's message cost baby his life' (7 June, 2002) 'Couple convicted of killing their infant son' (13 June, 2002) 'Convicted killers' (13 June, 2002) 'Dying baby couldn't speak out (14 June, 2002) 'Depressing idiocy' (15 June, 2002) 'A monstrous, lethal arrogance' (15 June, 2002) 'Widespread horror over Moorhead case' (18 June, 2002)</p>	<p>'Dead baby's parents charged' (27 February, 2004) 'Parents in court for failing to provide necessities of life (23 March, 2004) 'Prayer couple committed to trial' (16 December, 2004) 'Family prayed to revive dead baby, court told (18 December, 2004) 'Parents failed to get help for baby' (1 November, 2005) 'Family tried prayer to heal son' (11 November, 2005) 'Parents of dead boy not negligent says lawyer' (17 November, 2005) 'Couple not guilty of son's manslaughter (18 November, 2005) 'Trial highlights clash between parental rights and medical advice' (19 November, 2005) 'Convicted and discharged without penalty' (19 December, 2005) "'You've suffered enough" judge tells parents' (20 December, 2005)</p>

Figure 3: Meanings implied by language use in the New Zealand Herald.

However, in their role as human mechanisms of state control (Foucault, 1977), representatives of the police, lawyers, judges and judiciary all take part in condemnatory and dividing activities when necessary, which are passed on to the public through the media. Note, in the following statements taken from media sources, the apparent symbolism and therefore clear meaning in the judge's comments as reported (*italics added*):

While sentencing the couple, Justice Harrison said the most serious factor of the case is the Moorhead's *uncompromising dogmatic belief* that Caleb's illness was a test from God. He noted Deborah Moorhead's pregnancy but said that was not enough to prevent a prison sentence. He told the couple that *society had difficulty understanding their beliefs* but said *they are not being punished for their faith* ("Cop vows to protect unborn child", 2002).

In short, the Moorhead's had failed to seek medical attention for their child and therefore had to pay the price that *society* demands because it could not understand how their beliefs could support their decision. Yet, their beliefs had driven them to do what they did, and this statement seems to carry a particular meaning; essentially that there are legal consequences for those who do not conform to societal norms, mitigating circumstances or not.

In the following reports of a detective's opinions regarding the Moorhead's behaviour offered *after* the trial, a condemnatory approach is adopted. It suggests a possible threat to anyone else who may wish to live a 'deviant' lifestyle, and bring up their children in a different (not 'normal' fashion):

The policeman who headed the inquiry said the infant's death was needless. "The parents' strong, deeply held religious beliefs blinded them to the plight of their sick child...It has been a pretty tragic case and it was a totally avoidable situation," he said ("Cop vows to protect unborn child", 2002).

As the conduit through which symbolic meaning is passed from the authorities, the connection between State, judiciary, law enforcement agencies, medicine and the media is a frequent and constantly reinforced one (Foucault, 1977). Hence, in reporting the facts of a given case, the media often promotes the notion that the law supports modern medicine and frowns upon those who wish to care for their sick children in ways that are not sanctioned by the law/medicine/the general public:

According to the police, and especially the detective who led the police case for prosecution, the infant's death was needless. The couple exhibited 'deeply held and impenetrable religious beliefs that blinded them to the plight of their sick child. The verdicts sent a clear and strong message to those with a similar attitude towards caring for their sick children. "We have medical professionals for a reason and we have laws for a reason. That was graphically shown here today" ("Ordinary man's faith cost a life", 2002).

Other foretellers of future punishment associated with transgressions of the legal system, with a view to perhaps warn others who may wish to challenge the (medical-legal) system, also include those who would normally be seen to be more concerned with matters of jurisprudence or academia. Nevertheless, this advisory expert role does not preclude them from the use of symbolic representations of minorities in society (*italics added*):

Religious fanatics could be in for harsher treatment from the courts if the Moorhead case is used as a precedent according to an academic....Otago University medical law professor Peter Skegg says there have been other cases where parents have preferred alternative medicine which have not resulted in prosecutions. He says it appears parents from religious or ethnic minorities are more likely to be prosecuted than middle-of-the-road families ("Legal experts consider Moorhead case", 2002).

Such commentators are part of a 'Bourdieuian field' that stretches across the professions associated with the maintenance of the 'status quo' of the middle ground (police, lawyers, judges, physicians, academics, the state and others) the majority of whom are drawn from the middle classes themselves. The reproduction of middle class discourses in the media is a recognisable practice in the maintenance of the dominant social order, law and order, conformity and discipline from a privileged cultural and class perspective (Bourdieu, 1984; Foucault, 1977). As such, the media extends beyond the mere reporting of a given case and acts as a law enforcing conduit for the delivery of a wider opinion about the state of society. In the example below, the message to any parents who wish to challenge the right of the medical profession to treat one of their children with or without their full consent seems clear and unequivocal:

Detective Sergeant Chris Scahill say police will be advising CYFS that the baby shouldn't be allowed to stay with its mother. He says it's a tragic case as the Moorheads obviously chose their faith over their son's life. He hopes the heavy jail sentence *will act as a deterrent to others....* ("Cop vows to protect unborn child", 2002).

The media therefore plays a powerful role in not only reporting legal proceedings, but in reinforcing their conclusions, joining the judiciary in condemnation of 'deviant' practices, and supplying both covert and overt messages for public guidance. In this latter role, the media sometimes extends into delivering judgements themselves.

The media as critics and conscience of society

According to Lupton (1995), the media is predominantly conservative, in that media gives a greater voice to elite or professional groups rather than less powerful ones. As maintained by both Foucault (1977) and Bourdieu (1984), the media acts as *the reinforcer* of the views of the prominently conservative forces within society that operates within a system that tends to promote conformity and attack non-conformity. There are numerous examples of the promotion of health related parental conformity in the media (Cumming, 2005; Johnston, 2000; Ministry of Health, 2005; Walsh, 2001), and overt or covert criticisms of parental non-conformity - the degree of support and/or condemnation varying according to the degree of radicalness exhibited by the parents (as illustrated in Figure 3, for instance); but overall, many articles seem to represent and reflect the judgements of normality that are, as Foucault (quoted in Owen, 1994) claimed, everywhere. In the cases reviewed in this chapter, for instance, representatives of the media - who have already previously engaged a vast array of experts (school principals, doctors, specialists, and church leaders) to support their position - often supplied their final judgements in an editorial or as a post-trial summation. At this point, the degree of critical and negative judgement may vary from the relatively mild and noticeably softening judgements, as were evident in the mixed messages concerning the Williams-Holloways for instance - i.e. the noble struggle of the child, the parents' need for sympathy, the profound effect that the case had on the nation, the degree of public response, and the rightness of the medical profession and the wrongness of alternative therapies (Editorial, 2000); as opposed to the severe and notably hardening judgements meted out to the Moorheads - i.e. as holding 'fanatical' religious beliefs, and/or being part of a 'radical' or 'lunatic fringe', being ignorant vegans at the expense of their own child, spurning the absolute rightness of medical care, possessing a 'monstrous, lethal arrogance', and even trying 'to be God' (Witchel, 2002). Other parents in the remaining cases analysed are judged by the media and appear to fall somewhere in between.

There is a noticeable uncertainty in those editorials or afterthoughts that deal with resisting parents who are neither religious fanatics, or ignorant, or particularly 'culturally different'. Instead, judgements appear to become less aimed directly at resisting parents, and more towards those who seek to support the parents. For instance, an example of the media as arbiter of

decisions made by parents who are seen to be still part of 'middle society', but in a very difficult situation:

It is sometimes said by alternative therapists that healing is not the same as curing, and that death is not necessarily failure. Parents ought to be warned about that, too. Though the parents of Liam spoke often of his quality of life, there is no reason to think they settled for anything less than his long-term survival. Let's hope all the therapists in whom they had hope had the same goal. ... (Editorial, 2000).

In this instance, it is not the parents who are seen as 'deviant' at all, but rather the alternative therapists who might influence their decision. The alternative therapists' challenge that 'death is not necessarily a failure' is a clear deviation from an enshrined medical dogma that the ultimate aim is to control nature and prevent death (Foucault, 1975); they are subsequently viewed with media suspicion and caution because the acceptance of death is not a recognised part of the traditional medical response to illness (Lupton, 1994a; 1994b).⁶⁵ Those that are now recognised as belonging to a more traditional but not necessarily 'medical' response, such as chiropractors, herbalists, or acupuncturists, are usually left out of the media's critical gaze.

The critical intolerance of the media that is shown towards resistive parents and/or alternative therapists that are seen as outside the mainstream tends also to be shown towards any religious minority within New Zealand society. Media criticism in such instances is mainly towards 'fringe' elements of such groups rather than well established minorities (who have overall, been tolerated by society because ways have been found to deal with them that does not pose any threat to 'mainstream' society).⁶⁶ In this approach, the symbolic use of language is unmistakable when smaller and mysterious groups are targeted and the discomfort of the media spills over into judgements and recommendations as well: e.g. "Followers of *some lunatic fringe* of the Seventh Day Adventist" (italics added)... "no beliefs, religious or other, should be tolerated if they deny any child adequate medical care" (Witchel, 2002).

Summary

This chapter has examined the role of the media in the presentation of selected cases of parental resistance that have attracted attention in recent years. It has been argued that journalistic texts go beyond reporting 'the facts' of each case. Instead, the media provide clearly identifiable themes and human archetypes that are embedded, either covertly or overtly, within a range of discursive fields. Such themes were examined, and it was maintained that they varied in their presentation of resisting parents, but were usually negative or disapproving. In the media, there are discursive elements that connection field and cultural capital; the main association being a

⁶⁵ See further discussion in Chapter Seven.

⁶⁶ As is the case with children of Jehovah Witness families who require blood transfusions.

symbolic reflection of the 'mainstream', and the maintenance of mainstream values. The discursive field that is media, especially mass media, also presents children as innocents or even heroic figures battling against the odds; physicians and legal representatives as stalwarts of the (state) system fighting their own battles against parental ignorance, misunderstanding or malice; and the media themselves as defenders of fair play and decent behaviour in society. All, save resisting parents and their children, seem to be given every opportunity to comment in detail by the media, and medicine and the law have a great deal to say about them. It therefore remains to concentrate upon the related discourses of law, parents and medicine in future chapters.

CHAPTER FIVE

Law, medicine and parental resistance

I carefully guard against making the law. Rather, I concern myself with determining problems, unleashing them, revealing them within the framework of such complexity as to shut the mouths of prophets and legislators: all those who speak for others and above others. It is at that moment that the complexity of the problem will be able to appear in its connection with people's lives; and consequently, the legitimacy of a common enterprise will be able to appear through concrete questions, difficult cases, revolutionary movements, reflections, and evidence (Foucault, 1978, p.159).

Introduction

In this chapter, the law is examined in relation to the ways in which legal discourses are framed around cases of parental resistance to the medical treatment of their children and the ways that resisting parents are held liable before the law. The chapter begins with an exploration of the role of the law in cases of parental resistance, and provides an overview of current legal theory and processes in New Zealand; it concentrates on legal discourses within judicial sources, such as judges, lawyers, and the police. In particular, these discourses are analysed as they relate to medical discourses because the two fields are connected by their links to state power and control, and by their combined uses of knowledge as power. To further illustrate the responses of the law in regard to 'errant' parents, legal particulars from the five cases previously described in the first chapter are included, and additional cases are noted as required in support of the discussion. In this way, some of the ideas concerning the nature of resistive actions within hegemonic discourses and practices that were outlined in the previous chapter are drawn out even further.

To assist in the discussion on the analytical elements of legal discourses, the chapter includes selected ideas from Bourdieu (1977a, 1984, 1991) and Foucault (1972, 1975, 1977, 1979); it also contains key aspects of an analytical frame taken from Stychin's work on a critique of modern legal practices and their effect on a minority group (1995). Stychin's (1995) analysis⁶⁷ of the discursive elements and resistance towards homosexuality in law, with its frequent references to the social constructionist view of social identity and structured dualities lends itself to a similar analysis and deconstruction of the law's position regarding 'radically

⁶⁷ Stychin's analysis is elaborated upon through the use of discursive texts that seek to ground it in the concrete and situated experiences of political agents. This is necessary to articulate how particular subjects such as judges, lawyers and others take advantage of certain inconsistencies in legal discourse to effect change as they require it.

resisting parents.’ Furthermore, his elaboration of the pitfalls in the legal representation of artistic and pornographic representations that misrepresent marginalised groups in society and the subsequent problematisation of identity offer significant analytical weight to the debate. It will be argued that such representations are not far removed from representations of parental resistance; i.e. the view that individual identity is partial, contingent, and open to reconfiguration, but at the same time serves as the basis for assertions of collective identities (such as resisting parents) by particular groups (such as lawyers, judges *and* physicians) within society. Stychin’s argument that the tension between deconstruction and assertion of identity is irresolvable and best understood as a continuing contestation is therefore employed to analyse resisting parents.

The key arguments in this chapter are divided into three main discursive elements. In the first, which deals with parental identity and behaviours, it is maintained that parents are legally constructed in ways that are of benefit to the state but not necessarily for any parents who do not readily fit within (changing) legal norms. The notion of individualism and freedom of choice within society is therefore contentious. It is shown that in law, parents do not ‘own their own children’; instead they are guardians of their children until they reach an age where they too may become independent adults. It will also be argued that ‘legal truths’ are constructs shaped by social convention, and therefore the role of parents in society is highly debatable and constantly changing. When this role is legally examined because of parental resistance to medical treatment (and usually because a child has died because of it), there are further inconsistencies, not least of which being the legal response to the ascribed parental role of provider of the necessities of life. Secondly, it is maintained that the law seeks to regulate parental behaviour through the use of normalising judgements. Such judgements are based upon inconsistencies, indeterminacy and incoherence, and sometimes contradictory variations that have much to do with legal interpretations of parental culture, but far less to do with anything resembling ‘absolute law’ or ‘strict rationality’. In the three main variations of legal responses to parental resistance, it will be shown that parental resistance to medical propositions for treatment alone attracted a largely punitive legal response, even when in one case (Baby L) the resistance to extending the life of the child through continuing treatment came from medical rather than parental sources. Thirdly, the connection between state and medicine is extended further when the law seeks to arbitrate and delimit parental behaviour in a binary fashion noted as ‘ordinary v strange’. This intervention reflects both medicine and society’s propensity for separating certain behaviours into binary elements of guilt or innocence, good and bad, acceptable and non-acceptable. Such oppositions thereby make it easier to regulate behaviours in society, and at the same time to reinforce governmentality through cultural devices such as the use of experts, authorities, judges and lawyers.

The role of the law in cases of parental resistance

The five cases of parental resistance previously identified within this thesis all went through what is termed 'the due processes of the law'. In New Zealand, such processes are based on the judicial system, which is an elaborate refinement of "a means of creating some order in society by the evolution of rules, mores, and customs" (Johnston, 2000, p. 3). As a former British colony and Dominion, many aspects of English law persist, including the Westminster tradition of government, the use of common and statute law, adversarial court proceedings, jury trials and rights protecting the individual from the state. Hence, as is the case in the United Kingdom, the content of the law involves both substantive and procedural elements.

Legal theory and legal process

According to traditional legal doctrine, western law operates within the ideology of positivist legal formalism. This involves the belief that there exists the means to not only rationally categorise every human act, but also the expectation that every individual will meet the requirements of these categorisations themselves. If they will not, they face the consequences as administered by the state through its government and legal representatives according to 'due legal process' (Ross, 1959). To achieve this, the law not only selects what is rational behaviour (and therefore controllable), but also disciplines those who transgress. Such transgressions are perceived in legal proceedings as an insult not only to the state, but to rationality itself; Legal process is therefore considered to be the best way to supply a reasonably solid set of correct responses to any legal issues, operating from the principle of justice itself.⁶⁸ This principle presupposes that there exists a universal truth, or at least a rational answer for human acts, and therefore demands absolute and well reasoned objectivity, neutrality and 'disinterestedness' in its operation from the police to the judges. The neutral disinterestedness discourse is both powerful and unyielding; it dominates the processes of the law, and may be illustrated in an examination of the diverse ways that laws were, and are created to control individual acts that are perceived to be either irrational or undesirable within society. History is littered with such examples (Foucault, 1980e; Stychin, 1995)⁶⁹ and all five of the previously noted cases of radical parental resistance were judged by similar perceptions (see Chapter One). Thus, traditional legal theorists argue that legal processes can yield a relatively fixed set of correct answers to legal

⁶⁸ In 1934 the United States Supreme Court held that due legal process is violated "if a practice or rule offends some principle of justice so rooted in the traditions and conscience of our people as to be ranked as fundamental" (*Snyder v. Massachusetts*, 291 U.S. 97, 105 [1934]).

⁶⁹ One such case (which is now seen as a 'classic' account of an enforced response to *difference*), was that of 'Herculine Barbin' (1980f - Introduction by Foucault).

questions based on rationality and established norms or 'social conventions' in society. All that is required is that judges are objective, neutral and disinterested in their decision-making.⁷⁰

Substantive law in New Zealand includes civil laws and criminal laws; procedural law contains procedural rules (as in civil procedures and criminal procedures), and rules of Court (as in High Court rules and District Court rules). Civil law is the system of law that is based mainly on the use of statutes (Acts of Parliament) and uses an 'inquisitorial' (the judiciary seeks out the facts rather than dealing with only what is presented at the time) approach rather than an adversarial one, which applies in criminal cases. The judge's role is to investigate, with lawyers and the police there to assist the judge only. Civil law is mainly concerned with the protection of a person's private rights. On the other hand, criminal law is largely related to the common law system (i.e. a system where the parties involved present their cases and argue about their merits or otherwise before a judge and/or jury) that uses an adversarial approach. The judge's role is to deal with what is presented at the time, with lawyers for both the defence and prosecution of the person 'on trial'. Hence, Criminal law deals with the rights of individuals *and* society at large. In this thesis, 'what is presented at the time' is of pertinent to the discussion, because such material is essentially a collection of stories delivered by different people for sometimes different purposes.

In criminal cases (such as the Moorhead trial), the decisions of a higher court act as a binding authority on lower courts when similar cases are heard in future (but appeals can be made from a lower court to a higher one). In cases involving 'criminal activities', and as defined by the State, the present legal system is described as 'adversarial'. In this system, the parties, and not the judge, have the primary responsibility for defining the issues in a given dispute and for 'proceeding' with the dispute. The system is based not only on substantive and procedural law but also on an associated legal culture that has developed over time. The judge's role is therefore to preside over the activities within the court and to ensure that the proceedings are objective, neutral and 'disinterested'. In criminal law cases, the defendant is judged by a community of his or her 'peers'. As may be expected, the legal culture has its own language, ways of proceeding and deliberating. Yet, the very system that is thought to be fair, balanced and 'just' will be shown in later discussion to be complex and contradictory.

⁷⁰ As is maintained, for instance, by Kelsen (1967) in his influential text, *Pure theory of law*. His legal theory is based on the idea of a *Grundnorm*, a hypothetical norm on which all subsequent levels of a legal system such as 'simple' law and constitutional law are based.

Legal discourse

There are a number of post-structuralist challenges to the present use of both legal theory and processes in present day New Zealand society. For instance, the law cannot claim to attain a rational position concerning the 'truth' if all knowledge is contingent on social convention (especially through the use of language). As Bourdieu (1984) maintains, each social group will focus on certain 'rational arguments' or tenets favourable to their particular group; the law is really whatever the most powerful cultural group in society makes it.⁷¹ Those associated with the regulation and disciplinary procedures of the law possess a significant degree of cultural capital, be they law makers or law enforcers. Such a degree of cultural capital within a carefully delineated and controlled field allows legal representatives to not only regulate, but also to constitute the subjects of the law, namely the general populace.⁷² This applies as much in cases involving parental decision making for their seriously ill children as it would in any other cases. However, there are other pertinent issues surrounding legal discourse that may also have relevance to cases of parental resistance.

Legal discourse has been theorised in diverse ways. In Robert Alexy's *discourse theory of law* (1989), some confidence remains in the possibility of reaching just decisions discursively in institutional contexts. Alexy's legal theory revolves around his Special Case Thesis ('Sonderfallthese'), according to which legal discourse is a case of unfettered exchange of formal practical arguments, albeit a special one due to institutional, temporal and social constraints. Other theories of legal discourse take an almost appositional stance, arguing that the fundamental assumption that legal discourse is an instance of communication between free, rational, and responsible subjects under the objective conditions set by legal texts and discourses is a fallacy (Pickel, 1997).⁷³

The legal discourses that emerge from within the present system of law in New Zealand in relation to cases of parental resistance reflect the use and promotion of administrative and self-surveilling bio-power (Foucault, 1979). Biopower or 'bio-technico-power' was used by Foucault to signify the type of pervasive power networks that supply nationally sanctioned

71 The law may therefore be used to marginalize an entire cultural group, as occurred, for instance in the New Zealand law, when a poll tax was imposed on Chinese immigrants during the nineteenth and early twentieth century.

72 Similar arguments have been raised by legal scholars themselves, such as Kennedy (2004) in a post-modern critique of logico-positivist arguments such as Kelsen's. He argues that legal education reinforces class, race, and gender inequality in our society.

73 These theories shift the focus from the subject to the means of communication itself, in order to explore the undercurrents of legal discourse and question the entrenched claims of truth and justice raised by the law and supported by analytical legal philosophies. In legal interventions in cases of parental resistance of a more radical nature, it is an examination of the means of communication, i.e. discourses, that reveals such philosophical claims and therefore such legal consequences as occurs in these cases.

regulatory and interventionist control within a modern state. These power networks regulate state subjects through "an explosion of numerous and diverse techniques for achieving the subjugations of bodies and the control of populations" (p.140). Biopower presents as two major elements, which Foucault described as disciplinary and regulatory. Disciplinary biopower serves to define normal and abnormal bodies (as in medicine), and also as a self-regulatory force (as in, for instance, gendered ways of dressing, shaping and moving the body) through self-surveillance. Power networks therefore operate mainly through the use of *both* forms of *disciplinary* power (as "an anatomo-politics of the human body") and *regulatory controls* (as "a biopolitics of the population"). These mechanisms supply the necessary distinctions between anatomical and biological normalcy and unnaturalness, forms of self-regulation, and 'right or wrong' behaviours by which individual behaviour may be judged. It is a type of power that creates distinctions between things that privilege oppositional ways of thinking – i.e. male or female, sane or insane, or, to return to the thesis within this study, 'good parents' or 'bad parents'.

The binary distinctions that are prevalent within the use of biopower are preserved in legal discourses on parental resistance, and link directly to medical discourses through a common conduit that is a major pathway for the power of the state itself. This conduit is a direct result of the enduring class structure (that occurs within "structured structures" [Bourdieu, 1977a, p.72]) whereby 'experts' of law and medicine combine to influence the behaviours of parents in society. For instance, in most cases of parental resistance towards medical treatments, it is the medical consultants who take a case to court, and it is in court that they give their expert opinions, along with other selected experts from society, and it is within the court that every case is heard and judged by legal experts. It is the opinions of lawyers, expert witnesses and judges that are most authoritative, and a great deal of faith and trust is placed upon the telling, recording and judging of legal narratives. Thus, the power ratio between parents and legal representatives is made even more difficult in these cases where the law already works quite closely with medicine⁷⁴ because in both disciplines legal regulations are used to enforce changes in parental behaviour.

⁷⁴ Admittedly, there are cases when the law is not an ally for a member of the medical profession (i.e. cases of litigation for situations involving medical misadventure or error), but may remain an ally for the medical profession overall (by maintaining its own standards, punishing individual transgressors or impostors who threaten the reputation of the whole profession, etc).

The use of legal regulation to modify (parental) behaviour

Foucault maintained that governance or that of a centralised and expanding type of societal control by government is very closely linked to expert or professional knowledge, which itself connects to the construction of experts, institutions and disciplines. As Cheek (2000, p.27) notes: "This close relationship between power and knowledge can be seen in the connections between modern forms of governance and the discourses of human sciences such as medicine, psychiatry and the law." There are powerful ways in which the discourses of medicine, psychiatry and the law combine to construct an all embracing and authoritarian disciplinary force aimed at controlling the general population, but in ways that might seem quite acceptable to the public. Such power presents therefore not as raw, unbridled power, but rather as hegemonic but 'consensual' power, 'natural' rather than forced power, or 'normal' and legitimate power rather than seized power. Foucault often highlighted these connections or 'power networks' (1972, 1975, 1977, 1979), and explored how they were subtly maintained. One of his main conclusions was that there exists a series of persuasive 'authorities of delimitation' (Foucault, 1972, pp. 41-42) that operate through power networks that are themselves connected to the state's own superstructure, and hence, exist as separate entities but tend to work *as one*. One of the state's achievements in this regard is the keeping of records on every citizen, including records of legal decisions concerning the disciplining of its citizens.

Record keeping

In the legal system, the careful recording of 'the facts' and the use of previous cases to compare against (and to delimit) the behaviours of those brought before the system is an established practice that is considered to be a reliable guide to legal proceedings; there are numerous instances. Figure 4 (over page) is an example of the process whereby a judge will rationally examine previous cases for examples of similar acts to enable him to formulate a suitable opinion about the degree of seriousness of the case in hand, and to assist in the formulation of an appropriate sentence.

The judge's report (see Figure 4) demonstrates the use of legal consistency, where previous legal decisions are used to reinforce the present decision, which when cited during proceedings, adds a degree of validity to the findings of the Court. The connection here with medical record keeping is undeniable. Physicians too maintain formulaic and carefully constructed records that serve not only to guide current decisions about a particular patient's treatment, but to also guide others in doing so, and to act as a reservoir for future reference if needs be. To achieve this, every patient's ailments must become a part of an identifiable medical problem that can be labelled, categorised and treated in a rational fashion.

Sentencing of L and his wife on a conviction that without lawful excuse L and his wife neglected to observe the legal duty of parents to provide necessities for their child thereby endangering the life of that child; the child was diagnosed with bone cancer; it was made clear that if the child did not receive treatment he would die; the child did die six months later; the tumor on the child's leg was by then huge and was discharging onto a sheet;

Held, the appropriate course is to impose a sentence of imprisonment, but to suspend the sentence pursuant to s 21A Criminal Justice Act 1985; there are special circumstances which justified the imposition of the suspended sentence; the risk of re-offending is nil or minimal; alternative penalties such as periodic detention and community service would not be appropriate; sentence imposed of 15 months' imprisonment suspended for 15 months; further supervision for 15 months to enable L to have assistance of objective help in what will be a difficult period for them.

Statutes: Criminal Justice Act 1985 s 5, s 21A; Crimes Act 1961 s 152

Cases cited: R v Albury-Thomson, (1998) 16 CRNZ 79 referred to.

R v Hartland, 30 September 1982, Court of Appeal (NZ), CA175/82 referred to

R v Vaughan, 12 March 1999, Robertson J, High Court – Auckland, T121/98 referred to R v Griffen, 28 November 1990, Savage J, High Court – Wellington, T109/110/90 referred to R v Moore, [1954] NZLR 893 referred to R v Petersen; R v Peterson; Alt cit R v Brown; Alt cit R v Parker; Alt sp Peterson, (1994) 11 CRNZ 228; [1994] 2 NZLR 533; [1994] 2 NZLR 553 referred to.

Figure 4: Legal record keeping: R v Laufau 2 October 2000, High Court, Auckland; Judge J. Potter; T000759; Not Reported [2001] NZLJ 82; Criminal justice.

According to Foucault (1975), record-keeping about 'diseased individuals' in individual hospitals led to comparative investigations of hospital records and hence to the awareness on the part of doctors and others that there were disease populations. In this regard, medical records are a summation of a rational process to identify and 'problematise' every disease. In a comparable fashion, the law repeats a similar exercise. Through very particular and detailed record keeping, it may be argued that the law not only problematises certain cases of parental resistance, but provides detailed records for others within law to follow in similar cases. As legal discourses in this field tend to operate as normalising practices, it follows that in cases of radical parental resistance (i.e. that appear before a court of law), normalising practices problematise parental resistance, destabilizing it as human difficulties, and reordering it in order to be universalised through expert legal knowledges.

In such a fashion, mundane but highly systematic techniques of writing, registering and recording the details of every individual case eventually yielded epistemological returns, i.e. by turning a case into 'cases', or elements in series, that could be noted, listed, recalled and subjected to practices of 'optimisation'. In Bourdieusian terms, record keeping takes on even greater social significance, because such practices also act to maintain cultural capital inasmuch as it reinforces the views of the professional classes involved in the formation and maintenance of order through the use of state legislature. Such structural control over social space and activities therefore defines the principle of their rule (Bourdieu, 1984). However, in the case of record keeping and the use of legal regulations to modify behaviour, it is not so much a matter of overall societal control, but of categorised identity and roles as well.

Legal narratives

Stories are always about memory, and subsequently there is tension between the event as it happened (which can never be recovered under normal circumstances) and the process of telling the story. Such tension exists within the telling of stories within legal contexts such as legal/courtroom cases. In criminal law, stories are told in a certain fashion; that is, the story told by the defence nearly always varies considerably from that told by the prosecution. Similarly, stories offered by witnesses of 'the event', and by 'the accused' are often quite different (sometimes wildly so). Such stories therefore represent multiple retellings of what is considered to be the same reality for all observers, and are therefore aimed at getting to the underlying 'truth'. If stories are ways of knowing (i.e. providing an epistemological foundation), and also ways of being (because the ontological 'self' is embedded within such stories), then it becomes very important for each story teller to be believed and 'sanctioned' by the court; yet this can never be entirely possible. Instead, what becomes important is which stories take precedence over others, and under what conditions, or times, or places. This brings to mind Bourdieu's (1984) notion of habitus, but this time as a form of 'narrative habitus', or those stories that those who represent society feel 'right' with, and those that they do not.

In matters relating to parental resistance, there follows an excerpt of the judge's summation of the Laufau case at the end of the trial as one an example of the way in which 'legal stories' are told, and salutary messages dispersed to the wider public (Figure 5, over page). Note that in Figure 5, the emphasis on 'the value our society places on', the notion of 'the duty of the law' imposing greater responsibilities on parents than merely acquiescing to the wishes of their children, and the main difference between the wishes of a thirteen-year old boy and an adult. The excerpt is a brief example of a legal discourse that documents disciplinary actions against those parents who spurned medical advice for their seriously ill child. Yet, even in such a short extract, some of the central elements of Foucault's (1977) ideas on disciplinary principles - and especially his notion of 'normalising judgements'- prevail.

The first matter I must bear in mind is *the value our society places on the sanctity of human life*. The law recognises that young people are not necessarily capable of exercising the maturity necessary to take life and death decisions. Consequently, by section 152 of the Crimes Act the law imposes on their parents or their caregivers the legal duty to provide the necessities of life so that their lives can be protected and not exposed to danger. It will not therefore usually be a lawful excuse for the parents to accede to the wishes of a child when it comes to a matter of life and death. The jury did not accept that Tovia's wish that he not be returned to hospital, provided a lawful excuse that should have priority over the legal duty placed on Mr and Mrs Laufau to provide their son with the necessities of life, namely medical treatment. *The duty the law imposes on parents and caregivers is greater and stronger than the wishes of their children*, no matter how sincerely and strongly they might be expressed, and no matter how strong may be the wishes or the will of the parents to accede to the child's bidding. *It is one matter for an adult person with full mental faculties to exercise a right to elect not to undergo medical treatment. It is quite a different matter for the parents or caregivers of a child who carry the legal duty and responsibility to ensure that child has the necessities of life, to determine that the child shall not have medical treatment when medical treatment is necessary to protect his life*. In this case Tovia died and it was inevitable that he would without medical intervention. Mr and Mrs Laufau failed in their duty to ensure that he had essential medical treatment.

Figure 5: (Judge Potter, Sentencing remarks, Regina v P. & F. Laufau, 2 October, 2000, italics added).

The legal response to parental resistance

According to Stychin (1995), the law *needs* a contra-culture or 'other' (in his case studies, it was 'the homosexual') against which the norms of society can be measured and promoted through law. This type of distinction is based on *difference*, or a binary split between normal acts and abnormal acts; which in effect, is a split between the desirable norms and values of society, and the undesirable ones. In this thesis, the disciplinary binary discourse in legal proceedings is between the behaviours of 'normal' and 'abnormal' parental behaviours. Using Stychin's analysis (1995) as a guide, discourses about normal and abnormal parental behaviours are now teased out and presented as two major discursive themes (i.e. 'constructing parental identity through state legislation' and 'regulating parental resistance through the law') that illustrate the overall legal response to cases of parental resistance.

Constructing parental identity and behaviours through state legislation and jurisdiction

Foucault (1977) maintained that particular types of knowledge – such as the knowledge of medicine, law or psychiatry – equate to the power to not only inform others, but *define* others as well. This mode of knowledge/power was for Foucault an informative or liberating influence *and* a controlling influence; such knowledge may therefore become a domain of possibility as well as a mode of surveillance, regulation and discipline. In this regard, administrative forms of power tend to define the behaviours of others; that is, they construct the desired norms of others by acting in ways similar to medicine and psychiatry, through the application of labels, types, categories and rules.

According to a state supported guide to 'current social norms' (i.e. the law), a parent is:

The mother, father (natural, step, adopted or foster), or 'person in a parent role' of a 'child in a family nucleus'. A 'person in a parent role' is a person who is not a mother or father (natural, step, adopted or foster) of the young person (as defined by the survey) but who nevertheless usually resides with that young person. The young person does not have a partner or a child of their own and does not usually reside with their mother or father -natural, step, adopted or foster. Ideally, a person in a parent role can be considered a parent according to current social norms regarding parenting. (Statistics New Zealand, 1999b, p.10).

However, a parent may also be described as 'a guardian' as well, which is defined as:

Those persons, usually the child's genetic parents, who have responsibility for the child's upbringing. People who are not parents can be appointed a guardian by the Family Court where such an appointment is in the child's best interests... A guardian has the duties, powers, rights and responsibilities to be able to provide day-to-day care of the child and contribute to the child's development and determine, for or with the child, questions about important matters affecting the child (New Zealand Law Commission, 2005, Glossary x, xi).

In law, references are made to the roles allocated within society to 'normal parents' although over time, these references have changed in subtle ways, and no longer imply, as was once presumed to be the case, that parents were 'custodians' of their own children. In recent years, definitions of parenthood have allowed for more recent changes in society, such as the growing numbers of families where the parents are not necessarily the biological ones from a previous partnership:

"Parent", in relation to a child, includes a step-parent of the child, but only if the step-parent shares *responsibility for the day-to-day care of the child* with a parent of the child (Children, Young Persons, and their families Act, 1989, italics added).

However, for a more complex and reasonably up to date definition that better reflects current legal thinking, the Care of Children Act (2004) provides the following information:

The father and the mother of a child are *guardians* jointly of the child unless the child's mother is the sole guardian of the child because of subsection (2) or subsection (3). (Section 17. italics added).

Oddly, the law leaves it very unclear what the rights are of parents in relation to carrying out their responsibilities, for which we have to go back some years to those outlined in the Children, Young Persons and their Families Act (1989; Section 15):

For the purposes of this Act, "guardianship" of a child means having (and therefore a "guardian" of the child has), in relation to the child, (a) all duties, powers, rights, and responsibilities that a parent of the child has in relation to the upbringing of the child:(b) every duty, power, right, and responsibility that is vested in the guardian of a child by any enactment:(c) every duty, power, right, and responsibility that, immediately before the commencement, on 1 January 1970, of the Guardianship Act 1968, was vested in a sole guardian of a child by an enactment or rule of law.

Section 16 of the same Act (1989) outlines the duties and powers of parents through a legal interpretation of the roles of parents *as defined by the state* through its legal arm:

1) The duties, powers, rights, and responsibilities of a guardian of a child include (without limitation) the guardian's: a) having the role of providing day-to-day care for the child (however, under section 26(5), no testamentary guardian of a child has that role just because of an appointment under section 26); and (b) contributing to the child's intellectual, emotional, physical, social, cultural, and other personal development; and c) determining for or with the child, or helping the child to determine, questions about important matters affecting the child.

(2) "Important matters affecting the child" include (without limitation) a) the child's name (and any changes to it); and (b) changes to the child's place of residence (including, without limitation,

changes of that kind arising from travel by the child) that may affect the child's relationship with his or her parents and guardians; and (c) *medical treatment for the child* (if that medical treatment is not routine in nature); and (d) where, and how, the child is to be educated; and (e) the child's culture, language, and religious denomination and practice.

Roles such as those outlined above were once thought best left with the parents themselves, however in recent times this appears to be changing because the legal system now considers it appropriate to correct the mistakes of erring parents by means of 'parenting plans':

They [a judge and a barrister] identified the greatest advantages of parenting plans as their potential to educate parents about planning for the upbringing of children, to anticipate problem areas and prescribe ways of dealing with them, and to resolve and define issues for parents who wanted to be assured of their respective roles in relation to children (MacLennan, 2004).

'Parenting plans' are an example of both self-surveillance (they are intended to be drawn up by each parent), and collective surveillance (they are supposed to outline "how they [parents] will ensure communication, reduction of conflict, co-operation, assistance and promotion of the role of *the other parent*") (Ministry of Justice, 2001, p. 27; italics added). To reinforce the value placed by the state on good parenting, one of the roles of parenting plans is now clearly connected towards parents always acting "in the best interests" of their children, but now as defined and/or decided by legally sanctioned sources rather than parents themselves. This type of state surveillance therefore crosses over into an understated form of state control through the use of 'legal advisors' - as the following excerpt from two legal sources, a judge and a barrister cited in a legal article,⁷⁵ suggests:

Legal advisers have a professional responsibility to ensure that parenting plans are in harmony with the best interests of the child, say Manukau Family Court Judge John Adams and barrister Catherine Townsend. "A challenge exists for lawyers to add value to parenting plans by drawing upon their broad professional experience, beyond technical expertise. The competent lawyer will see a broader perspective than the immediate focus of most clients, and will be able to fashion a plan which develops the client's aspirations as a parent," they told the LexisNexis Child and Youth Law Conference (MacLennan, 2004).

This 'value adding' manoeuvre is quite subtle because it moves away from previous punitive or disciplinary punishment legal actions, yet also promotes normalising technologies based on the emerging science of 'parenting' through an attempt to use power productively. In short, parents are constructed through the prevailing structures of power as 'useful', i.e. good parents, but also as conforming, i.e. docile and malleable. Thus, recent legislation concerning children and their families has veered away from outlining the duties and powers of parents in favour of the promotion of what has been described as 'children's welfare and best interests' (New Zealand Law Commission, 2005). This manoeuvre, which is essentially recognition of certain rights of

⁷⁵ All of which, i.e. the players (judge and barrister), and the source (the Auckland District Law Society Journal/newsletter), gives the extract an authoritative voice from which to speak.

children, also defines and regulates parents' duties, rights and responsibilities and courts' powers in relation to guardianship.

The Laufau, Moorhead and Tribble cases that chronologically followed the Williams-Holloway case indicated an increasing readiness of the courts to hold parents who do not provide conventional medical treatment to their children accountable. In these cases (but note, not in the Williams-Holloway or Baby L cases), a jury was employed to judge the parental behaviours of fellow citizens according to categories supplied by the state to control the behaviours of its citizens *as parents*. In each case, the jury was asked to decide whether or not the parents had fulfilled their duty to provide their child with the necessities of life; and in each case, the necessities of life were argued by the court to constitute medical treatment. In the Laufau and Tribble cases, where it was considered that the parents had originally sought medical help but had not utilised it properly, the legal response was relatively lightweight;⁷⁶ however, in the Moorhead case, where the parents had sought medical opinion but then rejected it entirely, the legal sanctions were severe (i.e. five year prison sentences for both parents). What then, of the other two cases, where both children were still alive when the state was asked to intervene through legal means? In the case of the guardianship order that was placed on the Williams-Holloway parents, such early interventions appeared to be relatively powerless when faced with their determined actions to evade the law. In the Baby L case, the result was the death of a child, but with state sanctioned approval.

Two important distinctions seem to emerge from the previous discussion. Firstly, it seems apparent that the further parents are legally perceived to deviate from the *legal* norm, the more punitive the legal response; or, as one legal commentator maintains, it is one thing "where a parent is hampered by panic or threats or a desire to appease [the child]" but another when parents act in ways that are considered to be "seriously abusive or neglectful" (MacLennan, 2004). Consequently, resisting parents may be constructed in ways that blur the boundaries between resistance and abuse, which in legal texts, amounts to a form of slippage that may not be either well considered or deserved. Secondly, as an examination of legal texts reveals (and especially of various texts associated with each of the five cases), resisting parents are not just constructed within a spectrum of judicial culpability, but also in broader social structures, dispositions, and choices (Bourdieu, 1984).

⁷⁶ The sanctions supplied by the court in these instances were considered as adequate enough to maintain state control over parental behaviours via due legal process but stopped short of highly punitive actions, such as prison sentences.

Categorising parents through law

The function of law, once all powerful and in the hands of a very small minority (i.e. ‘the absolute monarch’ in Foucault’s description), became in more modern times a much more diffuse yet equally powerful force in the hands of the state (Foucault, 1977, 1980a). This was especially so for those for whom the state offered positions of power based on the attainment of particular kinds of knowledge, not least of which those with medical and legal knowledge. It may be argued that in modernity law has lost its central regulatory role to these emerging scientific discourses, both bio-scientific (medicine, anatomy, biology) *and* social (sociology, criminology, psychology, statistics) and consequently, the value placed by legal authorities on the construction and categorisation of others through an examination of their behaviours and/or position through scientific-medical discourses is considerable.

For instance, in presenting the background facts of the Baby L case to establish the parents’ and the medical authorities’ position, opinion was gathered or heard from an array of ‘experts’; the parents of baby L, for whom English was a second language, represented themselves with the aid of a lawyer:

Medical experts, as well as the Auckland Healthcare Ethics Committee, considered that discontinuing treatment would be in the best interests of the child. Baby L’s parents were unable to consent to this... Dr David Knight, Clinical Director, Newborn Services, National Women’s Hospital, was appointed as the agent of the Court for the purposes of medical investigation and medical treatment and management in respect of baby L... Mr and Mrs L were appointed as agents of the Court for all purposes other than those for which Dr Knight was appointed as the agent of the Court (Auckland Healthcare Services Ltd v L, 1998).

The parents of baby L were therefore categorised according to their being ‘other’ than medical rather than recognised as experts on their own baby’s welfare. Yet, they were perceived as being ‘resistive’ parents as well by the medical profession (irrespective of the fact that it was the doctors who resisted medical treatment in the Baby L case) and as such fell into the category of parents who were not acting in the best interests of the child. The best interests of the child, Baby L, were found in this case to be the withdrawal of life-support treatment in the interest of allowing the child to die, which in this case was considered a normal and rational event because:

There was no medical treatment that would have enabled the child to survive more than a few months, her chances of recovery were non-existent, she was suffering discomfort from the treatment, and it would be inhumane to continue with it (p 383, line 23; p 384, lines 6; 10)....

The rationality of this decision was explained as follows:

“No one shall be deprived of life except on such grounds as are established by law and are consistent with the principles of fundamental justice.” This section follows the provisions of part 6(1) of the International Covenant on Civil and Political Rights and was considered in the *Shortland* case. It was there accepted that the fundamental rights affirmed in the Bill of Rights are to be given full effect and a generous interpretation. However, this is a case which has similarities with the *Shortland* case, in that the proposed action will not “deprive” baby L of her life. What was proposed in this case is to withdraw treatment without which death would ensue from natural causes. Providing that it is in the best interests of the patient to withdraw support, in the circumstances there is no breach of the provisions of the Bill of Rights (Auckland Healthcare Services Ltd v L, 1998).

It was apparently rational to consider the parents' wishes as not being normal, or at least, as being less rational because it was not deemed to be within 'the best interests of the child.'⁷⁷

The parents' wishes, while of the greatest importance, cannot always be the determining factor. To abide by the parents' wishes and require treatment would be contrary to the best interests of the child (p 384, lines 30; 39) (Auckland Healthcare Services Ltd v L, 1998).

The legal precedent is therefore set. Parents may desire that their children live, even under difficult and medically supported circumstances, but doctors may desire that a child be allowed to die under the same circumstances.⁷⁸ Both apparently wish for the best interests of the child to be of paramount importance, but when there is infant suffering with no apparent resolution of the illness, rationality as defined by medicine is allowed to prevail. What then, of the rationality of parents?

Regulating parental resistance to medical advice through law

An analysis of judges' decisions following the hearings or trials involved in three of the five cases of radical parental resistance (that were introduced in Chapter One) that ended up in High Court suggests discursive frameworks that concur with both Foucault's (1977) ideas on normalising judgements (i.e. the imposition of certain ideas of normality that must be maintained when faced with any deviation), and Bourdieu's (1987b) view of the role of the law in not only interpreting legal regulations, but using them to endorse a correct vision of society:

The juridical field is the site of a competition for monopoly of the right to determine the law. Within this field there occurs a confrontation among actors possessing a technical competence which is inevitably social and which consists essentially in the socially recognized capacity to *interpret* a corpus of texts sanctifying a correct or legitimised vision of the social world. Such a process is ideal for constantly increasing the separation between judgments based on the law and naive intuitions of fairness (Bourdieu, 1987b, p. 817).

Thus in law, the desire to highlight and punish unacceptable behaviours (abnormal acts) overrides all other possible discourses on the nature of normality. In this regard, the ultimate aim of punishment through law is not merely to control the behaviour of an individual, but more crucially, to act as a deterrent to others. This particular aspect of social control or *governance* is often made quite explicit in judges' remarks when concluding a case and sentencing miscreants - for instance:

...two factors must take precedence in fixing the sentence. One is the premium which our society places on the value of human life, especially for the vulnerable — the sick and the young. If anything, the sentence I am going to impose is an insufficient recognition of the value which I place on Caleb's life. The other important factor is the requirement to send a deterrent message

⁷⁷ 'The best interests of the child' is discussed in greater detail in Chapter Three. However, in 'normal' legal interpretations of what may be in a child's best interests, courts usually rule in favour of the least harm for the child, and the most life preserving.

⁷⁸ This relates to the rational goals of medical treatment (see Chapter Three, pp79-80); i.e. if none are achievable, then treatment is withdrawn.

both to you personally and to those who may be tempted to follow the same course as you. Accordingly, I sentence each of you each to a term of five years imprisonment. Stand down (Judge Harrison, 2002, p.17).

Yet, in matters of judgement, it may be argued that the notions of rationality, medical and legal norms, and social acceptance may vary considerably according to the power of legal argument and the judge's decision making capabilities. What follows are three main variations of the normalising judgements of judges based on the 'five cases'. In each, it will be noticed, the blame falls almost entirely on the parents and never the physicians, who are always characterised as authoritative and knowledgeable. For instance, in the Moorhead and Laufau cases, it could be argued that the physicians failed to act appropriately because no-one appeared to ensure that procedures were in place to avert the withdrawal of the parents and child. If such procedures were in place, then they clearly failed; however this consideration is bypassed in court, and no blame at all is attributed to the medical system or its representatives. Overall, there is a perceptible tension between seeing these alternative possibilities as individual and/or isolated cases rather than collective problems. Subsequently, what follows represents a spectrum of legal narratives to perceived breaches of the law attaining to individually orientated parental responsibility in society, but never towards the health care system's responsibilities (or for that matter, the wider issues in society at large that may lead to such parental responses).

Variant 1: the parents' behaviour is highly irrational, resistant to medico-legal norms and socially unacceptable

In this variation, taken from the Moorhead case, the judge's summation of the actions of the parents was condemnatory in all aspects of departure from the norms of society, including an opinion highlighting gross abnormalities of individual and social behaviour. For instance, the Moorheads were found to be all three forms of variant 1:

Highly irrational and ill-informed:

...you then chose to disregard a series of more specific, well informed, warnings that Caleb would die...That you should have deliberately chosen to ignore this authoritative advice defies rational belief" (Judge Harrison, 2002, p. 13).

Strongly resistant to medico-legal norms:

Mr and Mrs Moorhead, there is one feature which permeates all others in my view. I am satisfied that the real or effective cause of Caleb's death was your uncompromising, dogmatic self-belief. The fact that the belief may have been based on sincere and genuine grounds is of little relevance. What matters is your blind determination to, in a series of deliberate decisions...to breach your lawful duty to obtain medical treatment for Caleb (Judge Harrison, 2002, p. 14).

Uncivilised/anti-social:

I simply note that a civilised society tolerates difference and diversity, even if it means holding an unpopular or even extreme view. By the same token, Mr and Mrs Moorhead, civilised members of a civilised society are tolerant and receptive to the advice and assistance of others, especially when it affects a child's life (Judge Harrison, 2002, p. 3).

Variant 2: parental behaviour as irrational, resistant to medico-legal norms, but with some socially mitigating circumstances:

In this variation, based on the Laufau case, the judge's summation is tempered by mitigating circumstances but the parents' behaviour is still considered as irrational and abnormal (and therefore attracting some form of public disapproval and legal consequence):

Highly resistant to medico-legal norms:

The offence of failing to provide a child with the necessities of life thereby endangering his life carries a maximum penalty of 7 years' imprisonment. In sentencing in this case it is necessary that I also take into account s.5 of the Criminal Justice Act which applies if the offending in issue caused serious danger to the safety of another person. I believe it is clear that the failure of Mr and Mrs Laufau to set medical treatment for Tovia placed him in serious danger for his life. Section 5 requires the Court in such a case to impose a full-time custodial sentence unless the Court is satisfied that because of the special circumstances of the offence or the offender the offender should not be so sentenced (Judge Potter, section 7, 2000).

...but socially mitigating

In the second instance, and even though the parents' actions are perceived (legally) as abnormal or deviant, other mitigating circumstances relating to the social acceptability of the parents' actions are taken into account.⁷⁹ Indeed, the numerous socially acceptable behaviours and traits of the parents are recognised by drawing a distinction between deliberate acts of malice against a child (and therefore society in general) and the Laufau's overall social worth defined through reference to intention and ideas about responsible and hard-working parents (italics added):

However, *there was no malice, no ill-will, no ill-treatment* towards Tovia. In fact quite the opposite. Mr and Mrs Laufau loved all their children. They believed strongly in the will of God and hoped that would provide healing for Tovia. It did not. Tovia was suffering from a disease which only the intervention of medical skill could hope to stem or alleviate. *Mr and Mrs Laufau are responsible parents and citizens. They are hardworking people who contribute to the community* and whose care is critical on a daily basis in the upbringing of their three surviving children (Judge Potter, 2000, p. 7).

There was a similar situation in the judgement in the Tribble case, i.e. "The Crown has argued the couple should have taken their son to hospital. The Crown alleged the parents prayed for his recovery, rather than getting him proper medical treatment." That was denied in testimony by the couple, who told the court they believed their son had the same tummy bug other family members had had and that his health was improving. Mr Tribble told the court during his evidence that two days before Caleb died, a public health nurse had told him to take Caleb to hospital, but had agreed it could wait until the next day. He said he did not oppose medication, including antibiotics ("Jury in infant manslaughter case retires", 2005).

⁷⁹ As could be argued in the Laufau case where it was claimed that physicians failed to act because they were influenced by the public interest, support and controversy that had previously surrounded the Williams-Holloway case.

Variant 3; parental behaviour as rationally motivated, resistant to medico-legal norms, yet socially acceptable

The remaining two cases involving Baby L and the Williams-Holloway's avoided the High Court, and therefore being tried by a judge *and* a jury. In both cases the parents were constructed as rational beings within socially mitigating circumstances, yet they were viewed as involving perceived acts of parental resistance towards medical treatment/non-treatment that required legal intervention:

Resistant to medico-legal norms

Court order made appointing Dr S, as agent of the Court and giving specific consent for L to undergo medical treatment and management as approved by Dr S; order necessary because L's parents will not consent to continued chemotherapy treatment but have sought alternative therapy; L has the right not to be deprived of life; without intensive chemotherapy L's death will be inevitable (Healthcare Otago Ltd v Williams-Holloway 2, 18 March 1999, Family Court – Dunedin, Judge Blaikie, FP012/23/99, [1999] NZFLR 804).

...yet socially acceptable

After the gravest of consideration, we accepted that this was one of the extreme instances where the Court must take responsibility for baby L in its wardship jurisdiction and that it was in baby L's best interests that the orders sought should be made. We were satisfied, after considering baby L's right to life, when contrasted with her right to be free from discomfort and pain, when considering her parents deeply felt wish for her life to be prolonged as long as possible even if, as would be necessary, that be by artificial means which in part add to her discomfort, baby L's best interests would be promoted by granting the application. In this case, adequate external and independent assessment of the medical opinion had occurred, first by the reference to the Ethics Committee and secondly by counsel appointed to represent the child (Family Reports of New Zealand, Auckland Healthcare Services Ltd v L, High Court, 1998 October, Full Report).

In each of these cases the parents transgressed medical norms by going against 'authoritative' advice from physicians and continuing to resist when it was inevitable that legal action of some sort would follow. Yet, on analysis, both present an insight into the remarkably inconsistent but ultimately authoritative (in a legal sense) discursive positioning of the medical profession (see Figure 6 below). Curiously, there is no explanation available as to why the Williams-Holloway parents were not charged with failing to provide the necessities of life for their son, Liam. According to Bayly (2003), the lawyer who represented the parents in the Baby L case, there are two significant distinctions between the Laufau/Moorhead cases and the Williams-Holloway case. Firstly, the non-conventional treatment sought by the Williams-Holloways was supported by a substantial portion of the public; and secondly, Healthcare Otago went to court and obtained a Guardianship Order during the child's illness, but in the Laufau and Moorhead cases, this did not occur.⁸⁰ That is, in both of those cases, medico-legal action did not begin until *after*

⁸⁰ Bayly speculates that it is possible that the experiences learnt from the application involving Liam Williams-Holloway impacted on the decision of the health professionals concerned. This was, in fact, the reason offered by at least one of the other health care providers at the time.

the deaths of the children involved. In any event, the fact remains that even though the Williams-Holloway's disobeyed an Order of the Court under Section 10 of the Guardianship Act, no legal action in the form of a prosecution or sentence followed. As Bayly (2003) points out: "It would seem logical however that should a child's parents disobey an Order of the Court under Section 10 of the Guardianship Act, as the Williams-Holloways did, this action could substantially increase the severity of any sentence imposed."

Liam Williams-Holloway case	Baby L case
Right not to be deprived of life – but not to be free of pain and discomfort caused by intensive medical treatment.	Right to be free from discomfort and pain caused by continuing medical treatment.
Parents wish to discontinue treatment that would prolong life by artificial means (opting instead for 'natural alternatives').	Parents wish life to be prolonged by artificial means.
Liam's death will be inevitable without treatment that will prolong life but cannot guarantee a cure.	Baby L's death will be inevitable without treatment but it is considered 'futile' because there is no possibility of cure.
It was not in Liam's interests to discontinue treatment.	It was not in Baby L's interests to continue treatment.
Liam will die prematurely.	Baby L will die 'naturally'.

Figure 6: The discursive positioning of the medical profession in situations involving life and death decisions.

The difference between the Williams-Holloway case and the others cases was seen by one solicitor to be that "they provided non-conventional treatment for Liam rather than no treatment at all, and their action was largely supported by the public" (Bayly, 2003).⁸¹ It could also be argued that the Williams-Holloways had initially sought and accepted conventional medical treatment but had later opted for less invasive alternative treatments in order to preserve their son's quality of life. Conversely, in the Baby L case, medical treatment was desired by the parents but seen as futile by the physicians attending to the baby. In effect, treatment was supplied but then withdrawn in accordance with a medical norm rather than a societal one; in fact, this norm overrode the parents' wishes to emerge as a legally supported and dominant discourse. In short, in both the Williams-Holloway and Baby L cases the courts deferred to the

⁸¹ However, it is wrong to presume that the Moorheads provided 'no treatment at all', in that the Moorheads made considerable efforts to apply alternative (mainly herbal) treatments in the care of their child. It is therefore of interest that such attempts are not considered by Bayly, a solicitor, as being any form of treatment whatsoever.

opinions of physicians and not to the desires of the parents. This is an example of legal case law setting precedents for where the boundaries for continuing or discontinuing medical treatment should be set. It is in itself, a way of delineating the field (see later discussion). What then, of the parents' positions? In both cases, social approval of the parents' actions was high; the degree of rational argument was considerable (at least from the parents' perspectives), and the position of the medico-legal discourse less certain.

All in all, as this brief outline of the legal responses to each of the five cases has illustrated, there are inconsistencies in the legal processes and judgements that are not easily explained. Nevertheless, there is a discursive explanation that applies to the ways in which parents are treated by the judiciary in all five cases regardless of their differences in perceived rationality and medical and/or legal norms. According to Stychin (1995), that explanation is not heavily dependent on rational or medico-legal norms, but on *societal norms* instead. For instance, Stychin argues that the construction of a "normal" sexuality (read parenthood) through legal discourse requires an excluded "other" against whom the former can be consolidated. In his analysis, homosexuality provides this oppositional 'other' against which heterosexuality is normalized. Similarly, the law uses a delimiting arbiter that is based upon wider social norms when 'framing' or contextualizing cases of parental resistance to medical treatment. This is apparent in those cases dealing with resisting parents because, as previously argued, the law cannot always rely on mere rational argument and medical norms alone. The legal construction of resisting parents as those whose acts are deemed to be in opposition to those of normal parents, is closely mirrored in the media where judgemental legal statements are converted for use in the public arena (see Chapter Four, p. 121); in this, the useful connections between law (as a state sanctioned forum of 'little dramas' for public digestion [Bourdieu, 1998b]) and media (as its willing broadcaster) is once again apparent.

The law as the delimiting arbiter of 'ordinary v strange' parental behaviour

Parents who spurn medical treatment for their seriously ill child, or those who seek to continue medical treatment for their child when doctors wish to end it, i.e. those that sit outside 'societal norms', may be perceived as 'strange' or 'difficult' by medical representatives such as doctors or nurses.⁸² If all attempts to change the parents' resistive viewpoints are thwarted, physicians may seek to employ a pre-existing legal rule whereby they may hold parents responsible under law for their resistance. Later, if parents are 'taken to court', then they come under the scrutiny of the law (and possibly by media sources) because they are perceived to be behaving in ways

⁸² This is discussed in greater detail in Chapters Seven and Eight.

that are different from the rest of society. In this regard, the strangeness or ‘otherness’ of the parents is implied one way or another by those who represent not just the disciplinary bodies in society, but the administrators of the regulatory controls as well (Foucault, 1979). In short, they are subject to a medico-legal gaze⁸³ by those representatives of power networks that seek to regulate others through the use of bio-power.

But where is the ‘strangeness or otherness’ of the parents in the Baby L case? In the judge’s summation of the case (Auckland Healthcare Services Ltd v L, 1998), the following was noted:

Having come to the view that it was in baby L’s best interests that the application be granted, it was necessary to consider the parents’ wishes. Although it was undoubtedly very difficult for them to express them, particularly given the stress that they were suffering from at the time and the atmosphere in Court, we understood that Mrs L believed that it was still appropriate to give baby L a chance to have some family life although she accepted the medical advice that baby L was in fact dying. Mr L felt, as did his wife, that he could not give his consent and, in short, we inferred from their comments that this Court must take the responsibility for making this decision.

There was no strangeness in the parents’ request that their child be given ‘some (family) life’; it was after all, a perfectly understandable and rational one from the parents’ perspective. Yet, to overcome the impasse, and to act in what they saw as the best interests of the child, the doctors took the problem to the law. The case was heard and judged, but in doing so, the law became the delimiting arbiter of what was rational and just.⁸⁴ To achieve an outcome, the case had to be ‘reclassified’ as an exception to the norm where the usual logic about preserving life had to be abandoned in favour of an alternative outcome:

The starting point is that, in all but the most exceptional cases, the Courts are required to take the necessary steps to preserve human life. An exceptional case does not involve a decision on whether to end life, but whether to prolong it by giving or maintaining treatment without which death would ensue from *natural* causes. (p 380, line 41, italics added)

The outcome is death; the rationale is that this is a natural end as opposed to an unnatural one. Once reclassified in such a fashion, it was easier to decide whether or not to support the parents’ position or the doctors:

To have abided by their [the parents] wishes we would have had to require treatment to be given or continued irrespective of the clinical judgment of the doctors involved and, in our view, contrary to the best interests of baby L. We were much assisted by Mr Asher, counsel for the child. He was satisfied that the conclusions of the medical experts were correct. He considered the possibility of baby L going home but concluded, rightly in our view, that it was not feasible to allow such a critically ill child to be in a position outside the intensive-care hospital environment. Mr Asher... was not able to oppose the granting of the orders sought.

⁸³ In this context, it is argued that a ‘medico-legal’ gaze is not necessarily an extension of the medical gaze, but a collective and coordinated response born out of a Bourdieusian like shared habitus (i.e. the use of rationality, close attention to record keeping, and the use of previous ‘cases’ to inform new ones) across two related fields.

⁸⁴ I.e. As an arbiter of not only establishing rational ‘truth’, but of also the right to life and power over death: “The secret ... form of the procedure reflects the principle that... the establishment of truth was the absolute right and the exclusive power of the sovereign and his judges...” (Foucault, 1977, p.35)

Irrespective of the degree of parental pleading to the contrary in response to medical desires to withdraw treatment for their child, and irrespective of arguments in support of any possible alternative responses to a serious childhood illness, the court chooses to be guided by the medical profession, who in this case, seek to sanction death, and does so by finding a rationale that enables it to make a decision without compromising the ethics of both the legal and medical professions. A ruling to end life is therefore made, and 'nature' is called upon to provide this service. The court subsequently reclassifies its primary role as the preserver of life; those who exercise power through the use of knowledge within discourse (Foucault, 1980a) and/or through the use of cultural capital (Bourdieu, 1987a, 1991), will find ways to exercise their prerogative to govern behaviour on behalf of society. There are also significant differences in rational argument, and medical and legal interpretations of parental behaviour, and certainly in variations in social acceptance or otherwise of the parents actions.

Maintaining the role as the arbiter of parental behaviours

The law holds its position and role as the arbiter of individual behaviour within society, and therefore parental behaviours by maintaining a civic face that operates through the positioning and selective use of expert opinion both outside legal proceedings (law professors, legal experts, and inside them as well (judges, barristers, etc). This form of expert led arbitration is neither neutral nor balanced - as Bourdieu (1987b, pp. 828-829) notes:

The difference between the vulgar vision of the person who is about to come under the jurisdiction of the court, that is to say, the client, and the professional vision of the expert witness, the judge, the lawyer, and other juridical actors, is far from accidental. Rather, it is essential to a power relation upon which two systems of presuppositions, two systems of expressive intention—two world-views—are grounded. This difference, which is the basis for excluding the nonspecialist, results from the establishment of a system of injunctions through the structure of the field and of the system of principles of vision and of division which are written into its fundamental law, into its constitution. At the heart of this system is the assumption of a special overall attitude, visible particularly in relation to language.

Expert opinion is either delivered within legal proceedings, which is duly reported in the media, or outside of legal proceedings, which is also reported in the media if deemed significant (see Chapter Four). Either way, it is an opinion driven by the additional credence of the cultural capital of the speaker, and so, the greater the status of the (legal) representative, the more likely it is that the media will relate his or her opinions.⁸⁵ In the following instance, the speaker is a

⁸⁵ These utterances are reflective of economic or cultural capital that reinforces the power relations which constitute the structure of social space. A major part of this process is the transformation of people's cultural habits or economic positions into symbolic capital that has legitimacy and is seen as real. The language of cultural capital is therefore not only a means of communication but also a medium of power; i.e. language provides symbolic power. In short, "The language of authority never governs without the collaboration of those it governs, without the help of the social mechanisms capable of producing this complicity, based on misrecognition, which is the basis of all authority" (Bourdieu, 1991, p.113).

medical law professor, Peter Skeggs, stating what would seem to be a logical (but disturbing) opinion: "...it appears parents from religious or ethnic minorities are more likely to be prosecuted than middle-of-the-road families" (Carrick, 2002). The speaker is stating an opinion that only serves to reinforce the Bourdieusian argument that cultural and economic capital does matter, and that it is only to be expected that those who are not the 'middle-of-the-road' are more than likely to fall foul of the law because of their differences (i.e. to be different or distinctive is to be visible). Ordinarity is therefore implied in being "middle-of-the-road", and the strangeness (or difference) in being a religious or ethnic minority. Nevertheless, there are parents who have not been prosecuted, ordinary or not, and law experts have noticed this as well:

Otago University medical law professor Peter Skegg says there have been other cases where parents have preferred alternative medicine which has not resulted in prosecutions (Carrick, 2002).

Thus, in an apparently 'neutral observer' fashion, legal experts opine in ways that reflect a readiness to examine the decisions of their peers in legal practice for the purpose of delimiting arbitration, or protecting the norms of law when others seek to challenge them. It is a way of governance through stealth, or as Foucault (1977) maintained, through the ability to define others and thereby regulate their behaviour through distant mechanisms. For instance, in the following extract (which refers to the Moorhead parents), another professor of law maintains that those parents who transgress the 'rules' of medicine can be delimited by direct appeals to an 'us/ordinary', 'them/strange' categorisation:

There will be some who, appalled by the religious motivation of these otherwise responsible citizens, will want to demonise their behaviour and denounce it as a further example of the consequences of religious extremism (Brookbanks, 2002).

This statement might also serve as a warning for parents who may wish to practice their religious beliefs in ways other than 'responsibly' which is defined by contrasting it with the demonic ways of extremism. The author both connects the parents (the Moorheads) to religious extremism and delivers a warning to any others who seek to emulate their belief system and practices in regard to medical treatment. While he places the Moorhead's religious beliefs well outside the norms of the more common religious belief systems such as Anglicanism or Catholicism, he suggests that even ordinary belief systems are not necessarily immune if they become an obstacle to normal medical practices:

While religious practice of itself cannot be accused of endangering beneficial healthcare outcomes, it is nevertheless clear that religious traditions and spirituality can sometimes harm clinical outcomes (Brookbanks, 2002).

This separation of what is essentially secular or state from non-secular or spiritual, in light of the 'scientific' or rational nature of bio-power, is perhaps no great surprise. What may be surprising is that medicine and law remain largely unchallenged in their 'othering' of spirituality and religiosity. It is as if there is but one way to respond to the modern world, which is the scientifically defined and rational way of objective based thinking. Anything that is contrary to

such a way is therefore always in danger of being perceived as ‘other’ if judged by those criteria. However, statements concerning the notion that religious traditions and spirituality could sometimes harm clinical outcomes may cause offence to some people. For instance according to Benor, a physician (in Shannon, 2001):

Prayer healing is practiced universally, with uncounted millions of laypersons, clergy, and growing numbers of health caregivers sending healing to those in need ...[although he later adds] ...Healing should not be given instead of ongoing conventional medical care without the consultation of a physician (p.258).

Hence, the separating statement (dividing state/medicine from the individual/spiritual) so commonly seen in either medical or legal discourses is often qualified when applied to parental resistance to mean only those parents who are religious fanatics rather than all parents who hold religious views, and especially (state) tolerated religious views. To dilute the effect, as it were, the situation is represented in this discursive qualifier:

In reality, as terrible as this tragedy is, the overall risk posed by parents who inadvertently or recklessly injure or kill their children as a result of firmly held religious beliefs is probably infinitesimal compared to the widespread practices of child physical and sexual abuse (Brookbanks, 2002).

Here, the legal commentator is basically maintaining that people should worry more about other transgressive practices in their very midst rather than the small numbers of those who resist in ways connected to religious practices. Nevertheless, differences between ‘normal’ belief systems and ‘abnormal’ ones are presented as a warning to others through appeals to reasonableness:

In that case [the Williams-Holloway case] there was a fairly widespread public perception that the parents' desire to protect their son from further suffering inflicted by the health system was justifiably held and that flight to pursue alternative treatments was *at least as reasonable* as handing the child over to health authorities. But in the Moorhead case there was no body of strong public support for the parents' actions. Most expressions of opinion suggested the parents' actions, however sincere their religious beliefs, were irresponsible and dangerous (Brookbanks, 2002).

In this it can be seen that a distinction is drawn between the actions of one set of parents against another; this is achieved by indicating that the difference is to be found in public opinion regarding in exactly what form reasonable treatment may take. That is, the Williams-Holloways sought alternative treatment that was publicly ‘acceptable’, but the Moorheads sought alternative treatment that was not.⁸⁶ Nevertheless, by adding to the discourses surrounding parental resistance, legal commentators appear to be at least partly justifying their privileged position in society by recognising that society can at times judge others by their deeds, and that

⁸⁶ Alternative treatments seem to belong to a number of different categories – at least in the public approval sense. For instance, providers such as osteopaths and chiropractors, herbalists or acupuncturists usually occupy a ‘respectable’ place in the public gaze, whereas iridologists, colour therapists or faith healers generally do not. These interesting differences clearly reflect what may be seen as a type of cultural or class distinction (Bourdieu, 1984).

these judgements can only therefore reinforce the 'we' from the 'they', the ordinary from the strange, or the 'good parents' from the 'bad parents.' In such cases, all the holders of the specialist knowledge have to do is point that fact out and they will remain recognised experts with power over others to define the abnormal and the ordinary, and to adjudicate in matters involving life and death. To do so requires them to support and take part in the (legal) regulation of the behaviour of others, and to reinforce the use of legal means of dispute resolution in cases of parental resistance. In such a fashion, parents who resist medicine resist the law, and the connection between the two - as joint arbiters of parental behaviours in cases of child related life threatening illness - is undeniable.

Summary

The law has been examined in relation to the ways in which legal discourses are framed around cases of parental resistance to the medical treatment of their children and the ways that errant parents are held liable before the law. In the early part of the chapter, an examination of the established aspects of the role of the law in a modern New Zealand society and its relation to parental responsibilities was offered. It was shown that even in this seemingly straightforward task, 'legal truths' are but mental constructs largely shaped by social convention, and therefore the role of parents in society is highly debatable and constantly changing. It is within this constant state of societal flux and changing meaning that the legal interpretations of parental resistance were considered. Guided by Stychin (1995), and using the 'five cases' as examples, it was shown that the law uses resisting parents as a contra-culture whereby differences between 'normal' and 'abnormal' parental behaviour may be differentiated for both surveillance and control purposes.

Three major discursive themes in the legal responses to such parents have been offered. In the first, concerning parental identity, the ways that the law constructed and categorised resisting parents were explored. It was shown that parents are legally constructed within society in ways that are of obvious benefit to the state but not necessarily for any parents who do not readily fit within changing legal norms. The notion of individualism and freedom of choice within society is therefore contentious. Parents do not 'own their own children' in fact; instead parents are guardians of their children until they reach an age where they too may become independent adults who have parental responsibilities of their own.

Yet, when the role of parents is legally examined because of parental resistance to medical treatment (and usually because a child has died because of it), there are further inconsistencies, not least of which being the legal response to the ascribed parental role of provider of the necessities of life. It is at this point that the law seeks to regulate parental behaviour through the use of normalising judgements. It was argued that such judgements are based upon inconsistencies, indeterminacy and incoherence, and sometimes contradictory variations that

have much to do with legal interpretations of parental culture, but far less to do with anything resembling 'absolute law' or 'strict rationality'. In the three main variations of legal responses to parental resistance, there was evidence that parental resistance to medical propositions for treatment attracted a largely punitive legal response, even when in one case (Baby L) the resistance to extending the life of the child through continuing treatment came from medical rather than parental sources. The connection between state and medicine extended further when the law seeks to arbitrate and delimit parental behaviour in a binary fashion noted as 'ordinary versus strange'. This intervention once more reflects both medicine and a preoccupation within society for separating certain behaviours into more easily attributable elements of guilt or innocence, good and bad, acceptable and non-acceptable. Such oppositions thereby make it easier to regulate behaviours, and at the same time to reinforce governmentality through cultural devices such as the use of experts, authorities, judges and lawyers. In Chapter Seven, the connection between law and medicine will be revisited.

CHAPTER SIX

The antagonism of strategies: Exploring parents' talk about the parent-physician relationship

“Well at least in my own experiences my vision of my child as a teenager, of the grandchildren of the future, and of all the things that exist in a parent's mind as a natural and almost unacknowledged evolutionary inevitability, slowly but very pointedly slipped entirely out of my consciousness” (Mary).

This chapter presents four parents' perspectives on the issues that surround parental resistance towards the medical treatment of a seriously ill child. It is parents - not physicians, or nurses, or lawyers - who must live with their decisions regarding acceptance or otherwise of medical advice concerning their seriously ill children. Such a responsibility, it will be shown, carries a disquieting and formidable burden for parents, and comes at a very high price in both emotional and social consequences. The chapter begins with a brief overview of the main analytical approaches to the interview material gathered from parents who participated in this study. One parent's story (Mary's) is used as a major guiding discourse throughout the chapter; it concerns a mother who supported her four year old daughter through a terminal illness. Her story provides a powerful central discourse of parental suffering, affliction, and eventually, resistive human responsiveness. This story, and its analysis, is supplemented by the discourses of other parents who participated in this research. The themes that emerge from all of the parents' texts are then combined to develop an analysis of parental resistance, its gradual emergence, its 'tipping points', eventual 'embeddedness', and consequences.

As in other chapters, the driving force behind the analysis in this chapter belongs to Foucault, especially his ideas on power, *résistance*, identity and surveillance (1977, 1979), and to Bourdieu (1984, 1985, 1990b), whose social theories about the multi-dimensional social field, class, and identity are employed to explore the discourses of parents interviewed for this thesis. Selected material is taken from Young, Dixon-Woods and Heney (2002), and Young, Dixon-Woods, Findlay and Heney (2002a) whose works on cultural discourses relating to children, parenting, caring, and cancer or chronic illness are incorporated where appropriate to assist with the analytical framing of the texts gathered for this chapter. Young et al. (2002, 2002a), and to a lesser extent of Dixon-Woods, Young and Heney (2003; 2005) also provide material that is used to assist in the process of surfacing the covert discourses that surround radical parental resistance. In particular, Young et al. (2002a) offer significant insights into the uncovering of the process of 'biographical disruption' that occurs when parents are first alerted to a looming medical crisis with their child. This process is significant because it alters the parental sense of self and social identity. These authors were selected because they follow a similar analytical path to that chosen by Lupton (1994a) in that their overall aim was to

“understand the cultural component of illness experience in late modernity” (Dixon-Woods et al., 2003, p. 145) and critique the traditional ways in which the needs and roles of parents had been conceptualised in existing research; and/or “illuminate the processes involved in how parents live with their child’s illness” (Young et al., 2002, p. 209).

From an analysis of the interview texts offered by parents towards this research, it is argued in this chapter that examples of parental resistance may be found in parents’ narratives when they are compelled by circumstance to enter a medical world that is both alien and challenging to their sense of identity and role (Grinyer, 2002). When this occurs, Foucault’s (1979) notions about the relationship between power and resistance is confirmed; i.e. where there is (medical) power, there is also the presence of varying degrees of (parental) resistance. It is maintained that whilst the medically orientated environment will naturally challenge the socially prescribed role of all parents, some will be affected by the medical environment far more than others. The medical field, its habitus along with relationships between parents and health professionals can be a source of frustration and anxiety that lays down the ‘seeds of resistance’ in some parents, and if these frustrations are not dealt with effectively through the maintenance of open, honest and altruistic relationships, then loss of trust may be the result. If trust is lost, then so too can parental faith in the health care staff; and if this occurs, then even hope itself may fade. Interviews with parents conducted for this thesis suggest that it is under such circumstances that resistance towards medical treatments grows. Parental resistance emerges through ‘an antagonism of strategies’ that involves the gradual appearance of a spectrum of possible resistive responses. These responses include ‘using the system and playing the part’ to ‘standing ground’, and taking back and maintaining control.

Parents’ stories

Mary’s story was selected to serve as the core of analytical discussion for this chapter as it illustrates a number of major themes that are central to the discussion on parental resistance. These themes include the difficulties faced by parents when they enter the ‘medical field’, the impact of power relationships and habitus within this field, the challenge to the parental role and identity, the gradual erosion of trust in medical services and professionals, the use of language as both a means to convey information *and* to promote conformity, and the gradual emergence of resistance (which includes the parent’s desire to be allowed to resist). Where appropriate, Mary’s story is supported by additional examples from the stories of other parents interviewed for this thesis. This serves not only to bring home the often hidden or ignored aspects of parental disruption, but also its emotional elements.

Mary’s story is loosely framed and supported by Young et al.’s (2002) exploration of parental identity, which explores becoming a parent of a child with cancer, being a carer and parent, parental identities, and the biographical work of parents. To preserve the full impact of

Mary's story⁸⁷ the narrative moves in a generally chronological fashion from the early awareness of the seriousness of her child's situation, to admission to hospital, through various medical treatments and procedures; to relationships with medical staff and incidents that caused concern, to the gradual realisation that none of the treatments had worked, and finally to the death of the child, and the many reflections that followed.

Mary's story

Mary's story concerns the illness and eventual death of her daughter, Jane, who was just of school age when she died. The situation that she and her partner found herself in occurred in recent times, and the memories of the events remained almost as clear as if they occurred yesterday. For Mary, the story begins with a situation involving her infant daughter that she thought would turn out to be "nothing in particular". It was Friday:

She had a hard lower stomach and I thought sort of nothing of it at first, and I look back and think that I'd noticed it from say 3 weeks before... and I thought it might be something as innocent as a hernia so we trotted along to the doctor on a Friday afternoon. ...And he examined her and ...was very professional so I knew something was up. And he was on the phone straight away and he didn't sort of say what was what ...And he said to me "that because it was a hard lump, I will say I'm concerned."

What followed this relatively brief initial examination only served to heighten Mary's anxiety considerably, as did the reception for her and Jane at the local clinic:

And then I was rushed down to the clinic straight away; he made me get ultra sounds done on Jane and I remember I was having a sob in the car on the way there thinking, you know, I was over dramatising it. We walked in and felt as though all the people knew that we were arriving; and we were sent through prior to anyone else so I thought this was all strange.

Mary's anxiety was not allayed in any way when one of "ultra sound ladies" told her that if it was one of her children that she'd be very upset also. It therefore slowly dawned on Mary that the situation was about a great deal more than "a simple childhood thing."

Becoming a parent of a child with cancer

In the following section of her narrative, Mary describes the process of being admitted into hospital with her child. The scheduling, the examinations, the initial diagnostic tests and the eventual delivery of the diagnosis all comprise that period called by Young et al. (2002) 'becoming a parent of a child with cancer'. The day after the initial consultation with the family GP, Mary and her husband Graeme took Jane to a large city children's hospital to see the

⁸⁷ That is, her narrative is a crucial discourse that must be heard in adequate depth. Without it, the accompanying analytical framing, discussion or theorising cannot properly represent other parents' stories that are suppressed, ignored, or placated in the more dominant discourses noted in other text related chapters (i.e. Chapters Four-Six, Seven-Nine).

paediatric oncologist where she was 'seen' by a physician in the Emergency Department and the news after the examination was devastating for the parents:

He said to me it was one of two types of tumours - one of them will need immediate treatment and the other one won't; and we'll take a blood test then you can go home. And if it's the immediate one [after the results of the test], then we'll give you a call to come back in.

Such news, so quickly on the heels of the alarming events of the previous day, did little to calm either Mary or Graeme, and Mary sought clarification, which was that both types of tumours were cancerous but one was much more dangerous than the other. Yet, according to Mary, the news that their daughter had a serious illness was not delivered in a manner that would be conducive to providing the parents enough time and space to allow the information to sink in, and Mary and Graeme were left to comfort themselves:

...as I recall it was a very short time that he spent with us, standing in the emergency cubicle. And basically he said, "It's 1 of 2 types of tumours" and then he left shortly. "Come back on the Monday otherwise", and just basically gave us direction as to what the next step would be; they'd give us tests, I think...

Mary was devastated⁸⁸ but managed to keep her cool until out of sight of her daughter:

And I mean, I held it together at this point; he [the doctor] definitely didn't stay with us very long and then I remember saying to Graeme's dad "I just want to go outside." ...and I remember walking from the hospital as far as I could get before I just screamed - it was just horrible.

Mary and Graeme (her partner) then had to wait during the entire weekend for any further information about their daughter's situation. It was therefore a difficult ordeal for them eased only by the fact that the family was in their own habitat, with their own familiar habitus and field, all of which was symbolised by their use of space and proximity:

...we moved the mattress into the lounge room and we all slept together - don't ask me why - and it was terrible. I can remember it feeling just really terrible. I remember Graeme saying, you know, trying to reassure me, "look it's not, it's not likely to be, you know, it could be nothing." But you knew in your heart of hearts that that wasn't the case. But there was still that want to try and deny that this was all, you know, that this was all going to end up being nothing...

Mary's desire that the crisis would pass and that it would all be found to be a mistake is a common phenomenon found in all parents who face a life threatening illness and/or the possible death of their child (Kübler-Ross, 1997). To ease the stress, the family attempted a number of distractions:

...we would go playing with the cat a lot, we had this wee cat and of course he was just so, and so [we had] lots of giggles as well - you know how when life is just really at that height, that emotional height, and you laugh as much as anything else because you're so wound up I suppose.

However, Monday morning brought with it heightened fears, and the level of fear and anxiety became unbearable:

⁸⁸ According to Comaroff & Maguire (1981), "malignant disease in childhood has particularly distressing emotive connotations, due not only to its inherent implications, but also, to its symbolic marking of the critical frontier of medical science (p.117).

We'd had a couple of days to really stew on it. Then shit, I remember when we drove in on the Monday morning, me and Jane's dad...you know we just felt like doing family suicide, we couldn't stand the thought of facing them. It was terrible.

This feeling of dread was not helped by the family being plunged into the new and disturbing environment of the paediatric oncology unit, where Jane was admitted for further tests. The surroundings remained an alien world for both child and parents alike as the family entered a different space, a different habitus, and a different field. Also alien to them, it transpired as the week progressed, was the exact nature of their daughter's condition which remained largely unknown to the parents, although as Mary felt at the time, "they all knew" (referring to the physicians and nurses) but she did not. Communication difficulties appeared to be one of the reasons for this lack of parental understanding of the situation in the first week of hospital admission. Mary felt that she had never really been given a complete explanation of her child's illness and the alarming situation that they now faced. Mary's talk about her experience of 'becoming the parent of a child with cancer' is also a major theme identified by Young et al. (2002) who suggest that this period is characterised by delay, the discounting of parents special knowledge of their own child, anxiety of being labelled as a neurotic or over anxious parent, and feelings of regret, guilt and self doubt.

Adjusting to the situation

Mary maintained that her highly subjective emotional involvement in the face of what she perceived as the physician's highly objective emotional detachment led Mary to adjust her communication strategy. She adopted a strategy whereby she gradually replaced her emotional subjectivity with greater objectivity to allow her to 'fit into' that field:

Over time I became so strong and able to stand there and take whatever they said to me...as objectively as they were talking about [it], and I felt that that it was necessary because it was really, oh, the whole thing, it was just a dreadful bloody time really.

In this fashion, Mary made an adjustment (reflecting Foucaultian [1977] notions of self-surveillance and conformity) in order to be the kind of person that would be able to facilitate the best outcome for her daughter (see later discussion, p. 162). This adjustment is reflective of the observations and actions of other parents in similar circumstances (Hilden, Daniel & Lindsey, 2003), and in keeping with the need to 'fit in' a new field when attempting to enter it from another (Bourdieu, 1984). At the same time, Mary realised that within the medical habitus, the staff wanted to maintain her position in the field as that of the 'other', and never as 'we'. Indeed, she felt:

..as though you're a hindrance to their process...that you're just this emotional baggage that they somehow have to work around. And its really insulting, and I think they dismiss you a lot or tell you things...I don't think that they are necessarily honest with you, although I know they try.

In short, Mary was alienated in part by the ward staff with whom she came into daily contact; and this feeling of alienation served to fuel her perception that 'they' (the 'others' in her world) were not being open with her, nor were they able to fully express the empathy and emotional

connectedness that she so clearly desired. As time went by, tests were completed, but Mary remained largely in the dark about what was happening and what to expect until a brief discussion took place between Graeme and herself and the physicians later in the week:

But that week was difficult with the tests and stuff and then they said: "These were the chemo drugs that we're going to give her" - they actually said to us, and I took responsibility I think. I always needed to know the picture in terms of, you know, what sort of prognosis they were giving her, that kind of thing.

Regardless of the parents need to know, when they were finally told that Jane had an aggressive malignant condition requiring courses of chemotherapy, and what therefore to expect, it was a mere two hours before the treatment commenced:

We were not told what we were facing until the Friday night - 2 hours before they began chemotherapy. Even after that had started, as it poured into her and she was prepared for this treatment; and they knew- they'd done a biopsy - they knew what they were dealing with. They had never made that entirely clear to us for reasons, you know, for reasons. I guess legal reasons.

The conversation on the Friday was in large part driven by Mary rather than anyone else, because for Mary, having information was a way of asserting or attempting to impose control in a situation that she experienced as being outside of her control:

So I don't think they always, from what I can gather, give that information to parents but I suspect it depends on whether the parents want that. And so I did, and I can remember saying, "what's the chance of..." or whatever. So possibly I pushed that, but initially they said that there would be an 80% chance of survival.

Yet Mary did not feel that she was ever given any treatment options before the treatment was commenced, and neither did she fully understand the ramifications of the proposed treatment regime:

There was not a single word said to me about that...and as time went on I remember one of the nurse saying to me not to pursue any other form of alternative treatment because it would only jeopardise her treatment. I mean we are sort of all conditioned to think the medical profession know best and have the very best of you know, technology and so on, and I think I thought cancer was so huge it has to be fought with these huge...you know.

However, with some of the important details of Jane's treatment regime finally delivered, that night, as treatment continued, Mary decided to challenge and 'bend' the rules for the first time.⁸⁹ She stayed in the ward through the night with her daughter, thereby resisting what she presumed was a unit protocol. As Mary noted...*"they discourage parents from staying in the ward with their children."* This first act of resistance was for Mary an act of parental necessity versus institutional objectivity, and discouraged or not, she stayed with her child through the night as

⁸⁹ Later in this chapter, such an act of early resistance is called a 'seed of resistance'. Mary's action is therefore of considerable significance as it marks a point where she first decided to challenge to the system.

the chemotherapy was slowly delivered by infusion. Even then, all was not peaceful for either, and Mary did not feel fully prepared for what eventuated:

So through the night, I slept in the bed with her...they woke me up at 2 or something, 2 or 3, to say that she hadn't wee'd ... Because of the amount of fluid they were putting through... they were really concerned. ... They said to me that the side affects of the chemicals that they were going to be using - this that and the other - one of them was that they needed to flush a lot of water through her, you know, saline or whatever, for the fact that one of these chemicals could burn the lining in her bladder and cause bleeding.... So this was like to me - I took the fact that they had said to me it would be the lining of the bladder and cause bleeding, I actually thought she was potentially going to die at this point. So it was a horrific... [Voice fades].

Mary fretted about a number of issues related to the side effects of the powerful drugs that were introduced into her child's system, and especially the one that involved potential damage to her child's bladder (Eiser, Eiser & Stride, 2005). This fear was not relieved when it was decided to catheterise Jane, but this was performed in such a way as to decrease, rather than increase, Mary's confidence in the staff. Jane was given a sedative and then the nurses tried for nearly three hours to catheterise the frightened child, causing a great deal of distress for both child and parent alike.⁹⁰

Settling into a different role

Following the dramatic and deeply upsetting incident described above, Jane's treatment continued for a considerable period of time and Mary settled into the role of 'being a carer, being a parent' which Young et al. (2002) describe as "a striking biographical transition" (p.210).⁹¹ That is, there occurs a fundamental redefining of self-identity as a passage is sought through the crisis. In this role, parents assume a complex range of overlapping and sometimes contradictory roles – as carers, as providers of emotional well being, as protectors of their own and their child's identity, and as guardians of their child's 'future selves', which is done by protecting and prioritising their children's interests. For Mary, the dual roles of carer and parent brought a continuing trials and tribulations:

They'd given chemotherapy for, I think it ended up being 3 months - 3 hits, 3 amounts, and 3 week cycles; and if she responded to the chemotherapy and the tumour went down in that week (it had grown phenomenally). She looked like she had a little pregnant belly - it was incredible, a week's growth. It was really something. So they said if she did respond they'd be able to operate and if they could get it all...

During this time, a degree of normalcy emerged for both child and parent as Jane responded to the chemotherapy treatment enough to undergo an operation to remove the tumour. However,

⁹⁰ The 'catheterisation incident' was "*just horrific... an absolute bloody nightmare*" for Mary and marked a turning point where her complete trust in members of the nursing staff began to waiver. This incident, and others that served to undermine her trust, is revisited in detail later in the chapter.

⁹¹ Because such parenting goes on within the hospital in front of the gaze of others, Darbyshire (1994) called this 'parenting in public.'

the operation was not a success, and Mary received further bad news. Jane required 'massive doses of chemotherapy' and the prognosis was now poorer than before. There followed weeks of uncertainty and anxiety as Jane received more chemotherapy.

Living with the threat

Jane did however go into remission for twenty two months after her treatment, during which time life returned to something resembling normal but constantly tinged with dread, or as Mary saw it, "*living in this sort of no-mans-land...*" Jane had six-weekly check-ups throughout this period, but each visit brought parental anxiety that the tumour may have returned and the dread attached to hearing such news. Mary attempted to 'read their faces' in an attempt to prepare herself for any bad news: "*Most check ups were always pretty terrifying. You lived in anxiety all the time and there was that horrible...*" (voice fades). On each visit, Mary tried not to allow her fear to overwhelm her. Nevertheless, the stress was considerable, and its effect on the family was felt most strongly in her relationship with Graeme. Throughout Jane's illness, he played a different role to Mary, usually being secondary to Mary, letting her ask the important questions and make the key decisions, and often 'not being there' (for instance, Graeme left to go the motel on the first difficult night of his daughter's admission). Such a situation, according to Young et al. (2002) is common, as the traditional gender divisions of labour appear to strengthen, often reinforced by the health care system, and frequently at the expense of fathers, who may be left out of the 'communication chain' between parent and physicians. In Mary's case, the stress of Jane's illness proved too great for her relationship with Graeme:

We separated for 3 months when Jane was in remission. I guess probably round about that time...when she finished treatment for the first time, we must have separated for 3 months then and then the 12 months later we separated permanently and then it was a few months after that she relapsed.

Resigning to fate

Jane's relapse came after almost two precious years of relative normality, and occurred around the same time as another incident that shook Mary's confidence in the nursing staff. Jane developed an infection through the Hickman line because of nursing inefficiency and carelessness. The subsequent manner of the removal and reinsertion of the line became a major incident for Mary that left a long lasting impression. This incident, as on previous occasions concerning catheterisation served to further convince Mary that the care that her child had received in hospital was sub-standard. This feeling has stayed with her ever since. Following the insertion of the new Hickman catheter, Mary was given treatment and/or care choices, one of which was to allow Jane to take part in a clinical trial to which she agreed although the experimental nature of the drug dosage caused her much concern. However, Jane relapsed quite soon after the treatment, and Mary removed her from the trial and took her home to the familiar comforts of their habitus, within their own chosen environment. The family was sent to see a

radiotherapy specialist but Mary wavered at his offer to irradiate Jane's tumor as a last resort, especially when told of the likely side effects the treatment would impose on Jane.

At this important decision making point, Mary experienced feelings of helplessness and uncertainty, which are common amongst parents dealing with their child's relapse after treatment (Grootenhuis & Last, 1997); for Mary, her uncertainty grew as she considered this final offer, and she started to consider alternative treatments. Mary turned down the offer from the radiologist, and her resistance towards any further medical treatment for Jane had solidified further by the time of the next visit to the oncologist. Once there, it seemed to her that because of her previous decision to refuse any further treatment for Jane, the family were being written off. Mary continued to refuse any further medical interventions and decided to press ahead with her own interpretation of alternative treatments, which were mainly in the form of dietary supplements for Jane.

Jane's inevitable demise was traumatic, but it was made easier because of one key element that Mary identified several times during interview – parental control. As Mary noted after they had returned home: "*And for the first time in the whole bloody business we felt like we had some hand in it and some say in it.*" Jane's death came after complications set in that were insurmountable:

But, at the end, ... her lungs were completely blocked up; which of course they didn't know what that was and that if she were in hospital they would have been able to x-ray and say whether it was pneumonia or whether it was the tumour blocking it. Another unnecessary thing really, she didn't need to have that done. It wasn't going to happen anyway. But it's like being at home she didn't have to go through that and then the other lung, she was drowning, so couldn't get enough air and she was leaning forward like this for weeks, it was amazing, it was like watching someone perform a bloody [inaudible] - you know just that spirit to stay alive.

Before Jane died, the family met one last representative of the medical system, a nurse doing research:

And then at the very, very end I had a nurse come out who was one of the senior oncology nurses who had been there for years [and was] doing a study into care. It was the first time I ever spoke candidly to any of them about my experience and how I felt about the treatment and so on and so on and he was trying to get support - he was doing his PhD - trying to get support for a care unit within the children's hospital.

By this time, Mary had "*had enough*" and candidly told the researcher what she really thought of the hospital-medical system (see later discussion) which by now had eroded nearly all of her confidence. She concluded thus:

And I don't know how people manage... I went through what she went through and when she did die it was to a certain extent it was a relief to know that she couldn't be harmed any more and she was safe and I am so grateful for the fact that at least I have closure. I feel terribly for those families that their kids have leukaemia and there's 5 years then bang a relapse and it goes on and on I don't, I honestly don't know how they do it.

Thus, Mary's narrative about the events that led to her daughter's death ends, but the 'biographical work' (Young et al., 2002), of supporting of her child's and her own identities, continues to the present. This preservation of all that was important about Jane and the constant

examination and re-examination of the circumstances and discourses that surrounded Jane's illness remain as strong now as they did some years ago. Since the death of her child, Mary has kept a diary, written material on her child in considerable depth, and mourned for Jane.

Analysing parents' stories

Dixon-Woods et al. (2003) offer an analysis of discourses concerning parents' accounts of dealing with childhood cancer. Eight discursive themes are identified: physical impact, psychological impact, social aspects, services, parents' role and work, disruption, process and language, and gender. Aspects of these themes are drawn upon in the following analysis of the narratives of parents interviewed for this thesis.

Mary's story provides details about her experiences with various medical representatives that illustrate the fabrication, control and resistance of parents within the medical system.⁹² Parents, unlike physicians or nurses to a lesser extent, are not in their own environment when attending to a seriously ill child in a hospital; they are placed within an unfamiliar field where the 'norms' are medical ones, and they are subjected to surveillance and controls within that system. In other words, they are 'fabricated' by the 'forces and bodies' of medicine and health care:

Our society is one not of spectacle, but of surveillance; under the surface of images, one invests bodies in depth; behind the great abstraction of exchange, there continues the meticulous, concrete training of useful forces; the circuits of communication are the supports of an accumulation and a centralization of knowledge; the play of signs defines the anchorages of power; it is not that the beautiful totality of the individual is amputated, repressed, altered by our social order, it is rather that the individual is carefully fabricated in it, according to a whole technique of forces and bodies (Foucault, 1977, p. 217).

In order to illustrate the 'whole technique of forces and bodies' involved in the 'fabrication' of parents of seriously ill children within the medical world, Mary's story along with other examples of parental responses to the medical management of serious childhood illness are analysed in depth. In all but one interview (where a father joined the interview after a period of time), the narratives are provided by the mothers of seriously ill children. To assist with understanding and appreciating the different situations and range of childhood illnesses involving the parents, the following is a brief synopsis of the other three parent narratives:

- Ann's story concerns the prolonged illness of her daughter who underwent several years of surgery and medical treatment from infancy to late adolescence for a chronic medical condition. Ann's daughter was therefore diagnosed with a disorder in infancy which affected the development and curvature of her spine. Several operations later, Ann's

⁹² In the next chapter, it will be maintained that their involvement is a type of organised surveillance, and connections made to the use of 'biopower' that both medicine and the modern state employ.

child is now almost a ‘legal’ adult, capable of deciding for herself whether or nor she will accept further medical treatment. While not strictly a story of a life threatening disease process, it is a story of a mother and child who have ‘grown up’ within the medical system over a long period of time.

- Rose’s story (with minor contributions from Steven, her husband) concerns the sudden life threatening illness of her 12 year old son⁹³ and the months of difficulty that ensued when a diagnosis was not forthcoming. Her story is compounded by the fact that Rose is a nurse. Her son woke up one morning unable to move and was admitted to hospital under the general paediatrics team where a diagnosis of “post viral, don’t know what’s going on and probably not a problem” (Rose) was eventually delivered. He took a couple of weeks off school getting his strength back but later the illness returned and there followed several weeks of readmissions to hospital, medical tests, disagreements about the nature of his illness, consultations with three different medical specialists from three different medical disciplines before finally the correct diagnosis was made and her son recovered.
- Yvonne’s story concerns the circumstances surrounding the difficult birth and then medical treatment of her son who was severely disabled and died before he reached 1 year of age.⁹⁴ Her child, Edward, was delivered early in hospital via caesarean section following the discovery that Yvonne was suffering from polyhydraminous⁹⁵ (although no one told her this at the time). When her child was born he was fitting, and had to be resuscitated. There followed a period of intensive care in the Special Care Baby Unit and Yvonne did not see him for the next three days. He was transferred to another large city hospital at five days old where the parents were told by a paediatrician that their child had an irreversible and severe disability of unknown cause. There followed weeks and months of discharges home and readmissions, characterized by extensive periods where she was left alone to care for her ailing child with only the support of a friend who was midwife.

The analysis that follows enables the experiences and views of the interviewed parents in the determination of their own child’s medical treatment to be explored; it also draws out the limits of parent and child self-determination in health care institutions, the threshold for the

⁹³ Who was of a similar age to Tovia Laufau at the time of his illness (see Chapter One).

⁹⁴ Who was of a similar age and disability to ‘Baby L’ at the time of her illness (see Chapter One).

⁹⁵ Which is a marker for foetal abnormality.

engagement by medical staff in paternal activities, and the consequences of health care situations that lead to parental resistance when seriously ill young children are involved.

The impact of the medical ‘field’

In Bourdieu’s (1984) explanation of the use of social fields, the ‘players’ in each discernable field, such as medicine, law, or parents, strategise within their own personal and collective (class) habitus within the field of cultural production, which in turn, is placed within the ‘field of power’ or contextual influence. The subsequent complicated interactions that occur within any given field are therefore neither predicable nor random, but complex and multifactorial. For instance, the practices of medicine are the product of a functioning ‘field’ whose specific logic is determined by certain factors (such as scientific positivism, treatment protocols, professional practices and institutional regulations) that constantly serve to delineate and contain the field. In the following instance, and although Bourdieu was originally speaking about law, the relationships between power and competence within the field of medicine may be seen:

...on the one hand, by the specific power relations which give it its structure and which order the competitive struggles (or, more precisely, the conflicts over competence) that occur within it; and on the other hand, by the internal logic of juridical [read medical] functioning which constantly constrains the range of possible actions and, thereby, limits the realm of specifically juridical [read medical] solutions (Bourdieu, 1987b, p. 816).

It is within the ‘play’ of this particular field of clinical medicine, that parents such as Mary, Ann, Rose and Yvonne found themselves trying to be parents and doing what they saw as their parental duties such as ‘everyday childcare work’ (Darbyshire, 1994). It is a field with its own internal logic, language and ways of operation (i.e. its own internal habitus). Mary described this field as being “completely unfamiliar” and found it to be alienating; she felt that the limits of her understanding of the field, and thus her competence, were sorely challenged:

I mean we were in the oncology ward - there was no orientation for us - this is where you are, and this is what it is. It was just; it took me some time to work out what that actually meant. You know, I can remember a nurse saying to me, “oh, and it must be a terrible shock to find yourself in here in this ward.” And I actually didn’t know what oncology meant. Oncology, haematology, isn’t it, and so it was all sort of... [voice fades] (Mary).

The strangeness of the medical environment is a feature that is well recognised in research with other parents in similar circumstances (Young et al., 2002); but this is overlaid by the newness and strangeness of the medical field that operates within such an environment. In Mary’s case, she responded to this strangeness by continuing to engage in the daily practices of parenting – staying within proximity of her child, trying to meet her child’s many needs, and remaining ever vigilant. Mary noticed that within the hospital ward life was going on in ways that were both familiar and unexpected. For instance, the juxtaposition of baby photographs and stars against the austere medical setting resulted in a kind of dissonance that was confusing for Mary at the time:

The other thing was when we walked in, this is so dumb now, retrospectively... they were having one of those photo competitions where all the baby photos of the nursing staff picks which one they were. So there was that on the wall and there was all these stars hanging from the ceiling and I

can remember thinking that these might be the pictures of the kids that have died or something - it was just - yeah, the stupid things that you, 'cos you're not familiar with it (Mary).

For Mary, the unfamiliarity of the hospital environment was a factor in her feelings of disquiet, even if the shock of being within the medical field dulled over time because repeated entries into that field result in an increased familiarity with the 'ways of doing things.' This may also occur when a childhood illness ceases to be life threatening for the child or becomes 'chronic.' In these circumstances, some parents become more 'field stable'. For instance, as Ann maintained:

... We'd been there like 18 days, but she has been in before. She was 3 when she had her first surgery and she was in for, well it was meant to be 3 weeks, but she got chicken pox so we ended up being there for 7 weeks ...and the 2nd time she was in, oh it was the end of '91, they just checked to make sure everything was fine. And then it was '97 when they took the rod out... now it's um this year and we've been, she was in here for 4 weeks, and yeah, now we're back again after having spinal surgery (Ann).

However, for those parents where the diagnosis and subsequent medical treatment is less certain, or the child's illness is much more life threatening and/or acute, then entry into the medical field is a frequently difficult or alien one (Young et al., 2002). The medical field cannot operate in isolation without contact with other fields. It is within these contacts with people who normally operate within other social fields that medical power emerges.

Power games – parental relationships with the medical team

Foucault (1977) maintains that in modern times, control of others is achieved through 'rituals of truth' that are embedded in dominant social discourses. That is, people do not possess power; rather disciplinary power is a technique or action that influences every individual in subtle ways:

...in thinking of the mechanisms of power, I am thinking...of its capillary form of existence, the point where power reaches into the very grain of individuals, touches their bodies and inserts itself into their actions and attitudes, their discourses, learning processes and everyday lives (Foucault, 1980c, p. 39).

Bourdieu (1977a, p. 93) terms such mechanisms "bodily hexis", noting that there are routinised performances embodied in the way in which people dress, stand, speak, think and feel. These elements affect and are affected by the habitus of an individual and therefore impact upon their access to and use of power within the field. In this view, bodily hexis is "the social made body" (Bourdieu & Wacquant, 1992, p. 127). For Foucault, power is not 'possessed' - it is exercised, and thus medical power is a continuous exercise of power and control that is deployed through ways of seeing, speaking, dressing and acting in interactions with others. In the health care context, the physician - through the use of the surveillance process called the 'medical gaze' (see later discussion in Chapter Seven) - seeks to exert power and thereby control events from an established position of authority. Rose, Mary and Yvonne experience their relationships with physicians as cold and depersonalised, even if their expectations were different. In all three instances, there lurk the seeds of resistive parental discontent to the habitus of the medical field

and bodily hexis of physicians that professional training produces. In the first instance, the consultant's professional power is unmistakable:⁹⁶

The [Specialist Consultant] was from an old school approach of "I am the doctor and I am right, and you won't challenge me", and we could see that in the way he even treats his team ...He's an older man in his fifties, up to sixty; he's not renowned for having a particularly good bedside manner (Rose).

In the second instance, the medical habitus produces a bodily hexis that in interaction with a parent is unemotional and distant. Mary comments about the esteem in which a physician was held by his peers; however she was less than impressed with his personal skills.

Professor S was just this doctor in [city x] and I think he's pretty highly esteemed... he's a nice man, but very removed, very cold; not cold, just very... I don't even know if that (Mary).

In the third instance, the combined effects of hospital routine and standardised medical training led to an interchangeability of position (surgeon) that clashed with parental expectations about the relationship, and Yvonne found that any notion of personalised continuity of care from a dedicated physician disappeared as she prepared for her Caesarean section.

...we had already prearranged for an elective Caesarean ...Our doctor, our surgeon actually, went on holiday for the surgery and that's why [another physician unknown to Yvonne at the time] ended up doing the surgery. [This is] because he kept me in hospital for three weeks, then he came in and said, 'oh, actually I'm going on holiday, this person will be doing your surgery.' And it's like, "hold on, you were my obstetrician, you should have told me that from the start if you weren't going to be there for it" (Yvonne).

There are established power structures within the health care arena, and power discourses between individuals, across individuals, and around them, be they medical staff, nursing staff, or parents. As Mary noted:

The power trip of all the nursing staff and doctors was revolting - you know keeping you waiting for the sake of keeping you waiting. 'Cos its like any office, isn't it, I mean there's politics there. Politics between the doctors and nurses, politics between the parents and nurses and doctors, and so on and so on you know. And for all the way that it all comes across to me or whatever, it's crap. The thing is, I suppose, too intimidating... I feel that there was no stress relief for us, nothing talked to us about stress and how to cope with it (Mary).

Other members of the health care team may represent less powerful authority figures to a parent, and are therefore easier to place in a more equal relationship, or even an inferior one if the 'parenting' experience is seen as an essential element by the parents for appropriate therapeutic or personalised responsiveness towards their situation:

We had a young social worker that was introduced to us and she was appointed to our case. She was younger than me and lived with her parents, and I found that quite stunning...so she was very... I mean I'm sure a lovely lady but useless, absolutely useless. I mean it's that thing that, you know, you're not stupid you want someone with credibility, someone who has been through something similar you know (Mary).

⁹⁶ Which is an example of the paternalistic model in operation (see Chapter Three, p. 82).

Nevertheless, there are times when medical power is exerted in overt and domineering ways that may include, for instance, a parent being controlled by simply being ordered around by a physician with little explanation, as Yvonne discovered:

...I was kept in hospital. And he just said, "you stay there", and that. They never even told me why I was told to stay in hospital. They just said, you know, it's just for the safety of the baby; you've just got excess fluid, just in case your waters break, the cord could come out first, and that. They didn't say at any time that it's a sign of something going wrong, and it would have better prepared us if they had (Yvonne).

Symbolic power (Bourdieu, 1990a), may reveal itself as a form of objectivity that treats parents as adjuncts to a medical 'case' rather than as vulnerable people in need of personalised care and compassion (Welch, 2000). In the following excerpt, Yvonne and her husband were ill prepared for the information that they were given, and treated in a brutal and inconsiderate way by a physician:

We got flown down to [a city hospital], and they said, 'these doctors are going to be having a look at your child.' They didn't say anything else – they didn't prepare us for what they said. They didn't prepare us at all. We walked in, the guy did the drop reflex⁹⁷, he looked at Edward [her son] and things like that and took us into another room, turned around to us and said: "He's more or less a vegetable, and he's not going to get any better. We don't expect him to live" (Yvonne).

The use of symbolic power in this extract is stark; within his own field, and with all of the status afforded to his own cultural capital within society, the physician bluntly goes about his professional business as if the parents were no more than casual bystanders to his objective assessment. As Yvonne went on to indicate, such statements cause some parents to wonder about whom exactly they are dealing with, what might be expected from them, and whether or not they are to be trusted.

Conversely, in relation to the use of medical power in a more equitable and balanced fashion, other parents may be treated differently according to their perceived position within society (Bourdieu, 1984). This is because the appropriate forms of capital are determined by the field in which they will be used. Capital represents the power of a person that can be used in order to improve their position within the field. Thus, because Rose was as parent *and* nurse, it could be argued that she had a greater amount of cultural and symbolic capital within the medical field than Yvonne, Mary or Ann. There was an opportunity for her to share medical power through association, use of language, or even through personal acquaintance, and therefore benefit from a more equal power relationship with physicians. However, when asked at interview, she maintained that her dual role as parent and nurse was of mixed blessings:

⁹⁷ The 'drop reflex' is a basic test of an infant's reflexive system whereby a baby is held and then 'dropped' suddenly whilst still in the hands of the examiner. The normal response is for the infant to splay its arms and legs. If no such sign occurs, then the prognosis is much less favourable.

...it didn't help ...it worked against me. I actually had my ID card on me one time and it was picked up on. And it was like [from the doctor] "oh, mum's a nurse". Another time I didn't have my ID card on and it was like, "I would have liked to have known that you were part of our organization" (Rose).

When her credentials as a nurse became known, Rose was discovered to be 'one of us', part of 'our field', and a person who knows and understands 'our rules.' By implication, if she did reveal her status as a nurse, Rose could be granted certain 'rights' not normally given to others; that is, as an 'insider', she would know the rules and be accepted as one of the wider group, and be given greater input, prestige and control over events. Such unspoken rules within medicine are based upon predetermined patterns (Welsh, 2000), and they covertly affect interchanges between parent and physician in ways that are often subtle and covert (Lupton, 1994a).

The language and rules of medicine

Both Foucault and Bourdieu offered commentaries on the use of language as a type of discursive power that controls others through discourses that are both subtle and persuasive. Bourdieu (1991) maintained that language is not only a means of communication but also a medium of power. Likewise, Foucault (1972) went to considerable lengths to show that discourse, and not merely language, lay at the heart of *any* system of representation of social realities. As a way of representing knowledge about a particular topic at a particular historical moment, discourse 'constructs' and therefore defines and produces the objects of knowledge of the topic itself. Subsequently, it controls how ideas are put into practice and it endorses the regulation of the conduct of others. In this sense, medical power within the field of medicine is a dominant discourse that enables its practitioners to proceed with the certainty that they hold the appropriate knowledge and public acceptance to do so. This type of acceptance is an unconscious form of self-surveillance (see 'Adjusting to the situation'. p. 151), as Lupton (1994a) maintains:

The Foucaultian notion of medical power thus extends the medical dominance thesis of the political economists by viewing power regulations in the medical encounter as even more pervasive, and even more subtle, simply because power is 'everywhere', enforced as much by individuals' unconscious self-surveillance as by authority figures (p. 112).

Medical language is used by health care professionals to not only communicate effectively with each other, but to also reflect and/or maintain the 'otherness' of medicine. The language of medicine serves as a type of symbolic code between health professionals that actively keeps 'outsiders' out of the field, and 'insiders' in a position of control over others. As Illich (1976) noted:

His condition is interpreted according to a set of abstract rules in a language he cannot understand. He is taught about alien entities that the doctor combats, but only just as much as the doctor considers necessary to gain the patient's co-operation. Language is taken over by doctors: the sick person is deprived of meaningful words in his anguish, which is thus further increased by linguistic mystification (p. 175).

However, the use of medical jargon did not stand out as being a major issue for the parents interviewed for this study. Instead, it was the ways in which language was used as a means of

control by physicians and nurses in their interactions with parents that made an impact on parents. For instance, some parents described feeling put down, or being told off, sanctioned, or subdued by exchanges with clinical staff over the care of their child.⁹⁸ It was as if, there were certain ‘rules’ that they were not fully aware of, or if they were aware of them, they were not consistently applied by physicians and nurses. The unspoken rules are a way of operating within a field that is reflective of the knowledge, behaviours and control mechanisms within that field. When parents consciously or unconsciously transgress the rules they are reminded of the terms under which they are permitted to ‘play the game.’⁹⁹

The unspoken rules within medicine are presented in both words and actions in forms that symbolise the power differential. Bourdieusian forms of symbolic capital, such as that held by physicians (e.g. prestige, honour, the right to make treatment decisions), are sources of social power. People experience symbolic power and systems of meaning (culture) as legitimate if they are considered to be natural and inevitable shared beliefs within society. Thus, when a physician uses symbolic power against someone who holds less power in that field (and seeks thereby to alter their actions), they exercise a type of control which Bourdieu (1990b) termed *symbolic violence*.¹⁰⁰ Physicians are able to exert such control through the material distribution of medical ‘goods’, and through language evident cognitive classifications of those who are ‘like us’ or ‘not like us.’ Subsequently, a parent will often feel a duty to heed and obey the physician’s wishes, whether those wishes seem to be entirely reasonable or not. Such is the nature of self-subordination. In some cases, the parent’s duty to conform is not only taken for granted, but enforced in ways that demean the role of the parent by symbolic actions rather than verbal communications:

He was very rude. He was Doctor X from up there. The first time we actually met him, he told my son [i.e. her other son] to shut up, ‘cause he was going through the notes. And I was thinking, ‘well, if you were a doctor, you would have already previously have read all the notes instead of being so rude’, you know, and we’ve never really liked him (Yvonne).

The rudeness of Dr X seemed to Yvonne to have transferred to other members of the medical staff, as Yvonne was to find on a number of occasions: “*When we used to arrive at SCBU,*

⁹⁸ Nurses’ attitudes towards parental participation in the care of their own child are mixed but some found that parental participation is valuable (Roden (2005); other nurses have indicated their concerns about certain parents’ abilities to provide care (Brown & Richie, 1990). Gill (1987) found that there were “real communication problems between nurses and parents” (p. 222).

⁹⁹ Illich (1976) argued that “like all other major rituals of industrial society, medicine in practice takes the form of a game. The chief function of the physician becomes that of an umpire. He is the agent or representative of the social body, with the duty to make sure that everybody plays the game according to the rules” (p. 208).

¹⁰⁰ Symbolic violence operates in a multitude of unseen and subtle ways (‘stealthy imposition’), often learned within state institutions (such as schools) and then played out in other institutions, such as hospitals. Symbolic violence is, therefore, a type of coercion used against others in society that uses symbolic forms to ‘naturalize’ existing social hierarchies, such as are found in dominant groups such as physicians within health care.

you'd always see lots of doctors around Edwards's crib, and then as soon as they'd see us, they'd all scatter in all different directions" (Yvonne). Actions that were interpreted as rudeness may have been reflective of the medical staff's inability to know what to say to Yvonne once it was known that her child's outlook was bleak; it may also be a medical response to parents who are labelled 'difficult', which in this thesis is identified as an early signs of parental resistance. An example from Mary's story illustrates the full spectrum of conformity-nonconformity that commences with a willingness to allow physicians to control both the material and intellectual aspects of caring for a seriously ill child while she dealt with the emotional aspects. That is, in the early parts of Jane's treatment at least, Mary was happy to leave the rational and objective thinking to the physicians and concentrate on her own subjective thinking. She duly complied with everything that was asked of her:

I know in my heart of hearts I was completely happy to assign over to them all responsibility. I think I had enough to worry about; the emotional aspects were too great (Mary).

However, as Mary eventually discovered, not only was she left out of the 'logical loop', but also left out of an emotional one as well. She had entered the relationship assuming that the physicians and nurses would treat and provide dutiful and compassionate care for her child. She very quickly realised that that was an unrealistic and naïve expectation. When this realisation became known to her, she began to interpret medical staff behaviours as a type of (symbolic) violence against her that eroded her trust in them:

I know from my experience there is no reason why those oncologists couldn't meet with every single patient and family in a present and human fashion. Its all very well to say that they're doing this all the time - it wears them down emotionally and they have to close off and so on - that's not true; there are other ways of dealing with their position and I think they have an obligation to do this as well. I think it sucks that they put themselves on these bloody pedestals (Mary).

Mary's understanding of the acts of the medical staff as a type of symbolic violence is further reflected in the ways in which a parental position is suppressed by the medical team as they 'police their own boundaries' by resisting the use of alternative medicines:

[responses to]...alternative medicines or anything like that were always negative. I never saw anything within the ward on any other alternative or complimentary medicine, and what you did see was just those really extreme cases where someone had gone and tried something and it had turned to crap...Totally not open minded (Mary).

When the 'way we do things around here' is challenged by a parent, or when the practices of the dominant group are questioned, then the social atmosphere seems to become more hostile.

When this occurs, parents may start to wonder why this should be so:

The atmosphere, as I mentioned, was tense, and due to the defensive and cagey behaviour of the nursing staff. I began to suspect that there had been some fault on their part. They went about their business in an explicitly dismissive manner to us as parents (Mary).

Questioning their authority does not sit well with many physicians; it is argued that the more superior they perceive their cultural capital and habitus, the more resistive they may become when challenged by others of a lesser capital (Bourdieu, 1984; National Patient Safety Foundation, 2002). This is attributed to the 'authority gradient' effect where in the interactions

of people in different positions of authority (power), the more junior member may be unsuccessful in communicating with a more senior team member, *regardless* of the content of the communication. In a similar way, when a physician is challenged by a parent on a matter concerning his field, and the way in which he operates within that field, then the response can be dismissive. For instance, after Rose told the supervising consultant physician that she did not agree with his diagnosis, which was later proved to be in error:

He [Consultant A] didn't say anything for months actually. Eventually we got a letter ...the letter we got was relatively apologetic, he sort of acknowledged it [i.e. a failure to correctly diagnose Nigel's illness], but [he] never saw him again. He just said, "needs a psych consult", wrote it out and the other consultant [Consultant B]... talked to Nigel about what he felt was going on and that his blood tests had come back, and what he wanted to do. It was at that point, that [Consultant A] still hadn't quite given it up and he was wanting to do [further tests] ...I think it was sort of a last ditch attempt to prove that his diagnosis was right and the other diagnosis was wrong (Rose).

Rose had broken a medical 'rule' by challenging Consultant A from her perspective as a parent and a nurse by doubting his diagnosis. The response was therefore dismissive and detached, and even resistant to contrary evidence. Such behaviours are reflective of both symbolic capital and violence, and the ways in which physicians respond to and judge the capabilities of the parents of seriously ill children. As Stein (1990) suggests, physicians tend to view 'good' parents as those who are quite likely to ensure their children are placed in the best position to respond to medical administrations, and who do not criticise their treatment plans by questioning the physicians or complaining about them. Similarly, physicians will be judged by parents in their communications with them, and if found wanting, then parents will respond in their own different ways. In both cases, a considerable degree of trust needs to be established between both parents and members of the medical team if the treatment of a seriously ill child is to proceed in a mutually acceptable fashion.

Trust-mistrust between parents and medical staff

Trust is seen as fundamental to physician-patient relationships (Balint & Shelton, 1996; Beauchamp & Childless, 1994; Mechanic & Schlesinger, 1996). If trust was either absent or eroded, it would be much harder for social networks, the 'reciprocities' that arise from them to operate, and mutually shared societal goals to be achieved (Bourdieu, 1986; Foucault, 1977/1981).

In Foucault's (1977) analysis, trust between people depends on the recognition of legitimate power and control achieved through compliance within close or distant surveillance. Subsequently, trust is indicated where there is least resistance to the order of things. Foucault called this type of control the "gentle efficiency of total surveillance" (Foucault, 1977, p. 249). This is especially so if and when one person's knowledge, and therefore power base, is recognised as greater than the other's, as might be seen between a physician and patient. This arrangement is a type of 'biopower' (Foucault, 1979) where an individual responds to subtle control and behaves in such a way so as to ensure compliance and conformity within normative

structures of behaviour in the context of social relations. In medicine, the aim is to 'have the patient want to take the treatment' voluntarily.

In Bourdieu's (1986) analysis, trust is essential for creating social bonds, distinctions or conformity within social networks and depends largely on mutual reciprocity and norms of action. He postulated that it was the social consumption of 'goods' which is either a material *or* an ideal practice (the latter being rooted in symbols, signs and codes) that is dependent on both economic *and* cultural capital (based on educational qualifications and cultural knowledge). Hence, social capital enables access to networks within hierarchical social structures. In medical care, where forms of social and cultural capital and knowledge predominate, these networks are essential to medical practice. They are one way that the profession is able to maintain its status in the face of the democratisation of medical knowledge, i.e. through 'gate keeping' activities such as the ordering of diagnostic tests, prescribing medicines, and referring to specialists and services. In return, the general public expects fair treatment and effective referrals and trusts members of the medical profession to deliver.

Narratives of trust and the breakdown of trust were present in the narratives of parents that were interviewed for this study. According to Carnivale (2005), trust between the parents of a seriously ill child and clinicians breaks down when there is a "clash of intentions". When this occurs, conflicting agents assign motivational aims to the other from their own respective understandings which contribute to a climate of prejudgement. Such a climate leads to the misinterpretation of one person's actions from the disparate viewpoint of the other, resulting in "an escalating cascade of silence and distrust" (p. 248). Using Mary's story as an example, the breakdown of trust for her most likely began when her daughter, Jane, required skilled nursing input. She did not pass urine after the commencement of her chemotherapy, and had to be catheterised. The child was given a sedative and then:

...they [nurses] took her into the treatment room and they spent at least I think it was 2 or 3 hours trying to insert a [catheter]... and it was just horrific, it was an absolute bloody nightmare. And I remember Graeme [who had returned] saying, you know, things like "naughty, naughty, stop it" [to Jane] you know...It was absolutely bloody awful and I was exhausted and they still couldn't get this catheter into her. And in the end they stuck her in a warm bath to try to get her to do wee's because they were really worried - and I knew they were worried and was picking up on this. I thought she might have died - I didn't realise this was a manageable, you know, or whatever...And it turned out that the reason they couldn't insert the tube the catheter was because the tumour was pushing the bladder to one side. And because it was in the middle of the night they didn't go and get her bloody records from another floor - if they had of seen them they would have known what they were doing and could have done it properly. I mean I was absolutely green so had no idea that they had done that and it was just, it was unnecessary and it was horrific (Mary).

Mary's confidence was shaken because efficient child and parent support and staff skilfulness is seen by both parties as an essential element in any parent-medical team relationship. Parental faith in those who seek to represent, instigate and control medical events may be shaken if it can be shown that due care has not been taken. In Mary's case, a type of 'negativity' surfaced as a result of this experience and remained a feature of her relationships with the medical staff from

that time on. In large part, it was not that the medical staff made mistakes (as is possible in any difficult situation) that annoyed and upset Mary, but the fact that they tried to 'cover them up':

We all make mistakes in all our jobs, and there were those who really covered up, you know, and you know that. And as soon as that happens, in that atmosphere - people aren't stupid, you know, parents know that things are covered up. Probably rumours go round too and I'm sure there was a hell of a lot more than I ever knew about and I never took notice of what happened with Jane. And mistakes were made you know, and it's really hard (Mary).

In Mary's narrative, there were at least three such 'cover ups', the catheter incident, the use of a massive chemotherapy drug dosage on Jane that was unbeknown to Mary, and a final incident which occurred nearer the end of Jane's treatment. Because of previous two incidents, Mary was much more sensitised to the otherwise inexplicable signs amongst the staff that something had gone wrong. According to Mary, it was this last incident, above all others, that sealed her distrust of the medical staff once and for all:

Jane's blood counts had dropped, as expected, and she was brought into hospital with an infection of some sort. The usual exhaustive tests were done to isolate the cause of infection, while, with no time to lose, several different types of strong antibiotics were administered. The atmosphere, as I mentioned, was tense, and due to the defensive and cagey behaviour of the nursing staff I began to suspect that there had been some fault on their part. They went about their business in an explicitly dismissive manner to us as parents (Mary).

Mary's suspicions were eventually confirmed when she was later told the reason for Jane's infection:

It turned out that Jane had developed an infection through her Hickman line. The Hickman had to be removed. This was because the nursing staff had overlooked putting the necessary fluid (jelly type material) in the tube to block it and keep germs at bay after the previous treatment. I was never told this officially (Mary).

This unhappiness was compounded for Mary shortly afterwards when she was called back to the hospital to comfort Jane as the nurses performed a procedure that was for Mary, both uncaring and inconsiderate for child and parent alike:

I left Jane in the hospital that night with her Auntie (a rare thing to do), and went out with friends... I returned to the hospital, early and tired, and was advised that the Hickman was about to be removed. Within half an hour I was in the treatment room with Jane, having to hold myself together as best I could, while they literally ripped the tube from her body ...The relatively inexperienced nurse who first tried to remove the tube struggled so much that in the end one of the senior nursing staff took over the job. If you have ever seen a Hickman being removed you will understand the horror of the situation. The sound of it ripping away from the gristle it was sewn to still haunt my memories today. Added to that of course was the usual fear and trauma that Jane regularly endured ... I did not have time to get anyone else in to support me through this, and did not feel, as I say, in much of a resilient state to cope well with it all (Mary).

As on previous occasions, this incident, and especially the cover up that surrounded it (she was never officially told why the line had to be removed), only served to further convince Mary that the care that her child had received in hospital was sub-standard. Even worse, her lack of confidence and trust in the clinical staff was now profound. This feeling has stayed with her ever since:

I resent enormously the fact that they did not tell me as soon as they knew. Although I appreciate their reasoning ...it was not a decision they should have made. I had no desire to be cushioned from the reality I was living in, and in fact they left me completely out on a limb, ill-equipped to meet with the force of circumstance. I accept that human error is inevitable, but dishonesty is a choice. I

resented more their hiding the facts from me, and trying to cover up their mistake, than I did that a mistake had been made. I felt throughout the process of Jane's treatment that the medical profession were ever conscious of legal ramifications and found it very difficult to cope with the air of secrecy and adversity that permeated the experience (Mary).

In summary, if parental expectations of good interpersonal relations, reciprocity, competency and honesty are not met, then trust between parents and clinicians will start to break down; this is because, as Carnivale (2005) maintains:

Patients, families and clinicians confront an inescapable interdependence within the context of disparate moral frameworks. These encounters gave rise to ambivalences and disagreements that could be traced to broader disparities. These persons struggled to agree on courses of action, while they held significantly different views, striving (and expecting) to have their own particular views respected (p.248).

Although it is quite likely that many physicians and nurses would deny that dishonesty is a normal responses to incidents that may occur within health care settings, the real or imaginary presence of such a disparity may cause a parent to lose confidence and trust in the clinical staff. This may contribute to "a climate of prejudgement" (Carnevale, 2005, p. 248) where (parent) misinterpretation can result in distrust of the staff. The biomedical contextual framework within hospitals is difficult enough for parents, and it is quite possible to imagine the damage to their trust if in their day-to-day practices, clinical staff does not maintain an adequate level of honest and open communication. The medical habitus, and the ways in which its rules and methods are explained to parents, is therefore highly influential in parental responsiveness to medical directions for treatment.

The effects of medical habitus

The medical habitus also plays a key part in parental perceptions of their relationships with medical staff.¹⁰¹ The health care setting, which is so 'normal' and taken-for-granted by medical staff, represents a significant change in field *and* habitus for parents that may well go unrecognised by some medical professionals. The impact on physicians of medical habitus begins in the training of junior physicians who begin rapid professional education and an intense enculturation processes when they enter medical school (Luke, 2003); processes that become so engrained that, as Bourdieu (1977b, 1984) suggested, they become embodied. Bourdieu maintained that these 'deeply structural' classificatory and assessment propensities are socially acquired, and manifested in a range of outlooks, opinions, and embodied phenomena (i.e. bodily hexis). In the medical arena, these embodied phenomena are largely taken for granted and unremarkable, but according to Young et al. (2002), parental unease begins when they enter the completely different environment of the hospital ward or unit and witness some of

¹⁰¹ More discussion on this topic from parents' perspectives is provided in Chapter Seven.

the effects of the medical habitus. For instance, in Mary's narrative, the medical culture within the ward/unit, hospital, and within the health care delivery system (and all of its unconscious structuring) represented a significant hurdle to her habitus which was within her field of control:

...you go in there and there were procedures and protocol and stuff so they would do the ultra sound and you were on bloody tender hooks and you're looking at their expression trying to work out what was coming and trying to take it all in. And then the doctor would come in look and then you were told nothing and you've got to wait until you're sent to the oncologist and then you go and see them and then you're given the picture (Mary).

That the procedures and protocols usually occur within a hospital was accepted by Mary (although such procedures have unnerved other parents, such as the Moorhead and the Laufau families), but she was still on 'tender hooks' as she awaited the findings of such procedures within such an alien field of operation. For instance, when her child was first 'seen' by a physician in a clinic attached to a hospital, which was in an Emergency Department side room or clinic, she experienced a strong element of 'gate-keeping' behaviour within such a department that permeated all of the staff from the receptionist to the Consultant physician:

They were really aggressive. And whenever she was admitted she would go through Emergency [department] as part of the routine which was where all the germs are. And here's this kid with no immunity; that was hard to handle, [then] you've got trainee people working on your child that you know are doing things wrong, you know because you've seen it done 3 million times before and they're making the job so much harder. I mean something as simple as a finger prick is nightmarish for a kid - yeah, there's no privacy ...there's a lot of things (Mary).

Mary was concerned because she saw an Emergency Department clinic as an unsuitable place for her child's health ("*where all the germs are*"), for proper discussion of her child's illness ("*no privacy*"), and for her child to be assessed properly ("*trainee people working on your child*"). Rose also commented on the use of the Emergency Department to gain access into the hospital proper. She too had to undergo an extensive wait with her ill son in the Emergency Department whilst protocols were followed, and the appropriate physician was contacted (a Registrar), and then found the time to go to the department and assess her son's condition:

...it was a six to eight hour wait to get him to a ward where they could start properly looking at him. And that to me was extremely frustrating to the point where I wanted to scream for some administration help in getting it sorted. It was just crazy...That's just waiting in the Emergency Department. So the triage nurse would come and find this kid who was unable to walk, and sit us in a cubicle, as you do. And we would say, we've got a direct admission" and he would say, "Oh well, you still have to be assessed." So actually it made no difference (Rose).

Thus, even for Rose (who was a nurse and a parent), the medical habitus caused frustration. She had to "wait six to eight hours" in the Emergency Department; her child had to be assessed there, regardless of being a direct admission patient, and she, like Mary, found it all to be a cause of anxiety and resentment. Such protocols as waiting to be seen, being assessed, having preliminary tests, and being admitted are all parts of the entry into the medical environment, which in turn is ruled by medical habitus. It is therefore also controlled by a power/knowledge nexus where both are mutually constitutive; i.e. knowledge is perceived to be historically specific and therefore always implicated in questions of social power (Barker, 2003). Such

power underlies the medical role of directing a patient towards medical treatments and procedures. But as Mary maintains, such power and control without a feeling of humanity is disturbing:

They could put certain procedures in place. ...But the thing I found most difficult, and I guess I resented the most was the lack of human qualities about them - all the procedures in the world don't cut it for me, you know (Mary).

Other interviewed parents such as Yvonne noticed this as well. As she stood by watching her infant endure fit after fit, she was asked to sign a consent form with little discussion or preparation:

...he was just twitching kind of thing and then they said, "He's seizing, would you mind signing this." They were going to give him an anticonvulsant that they didn't use in New Zealand before (Yvonne).

It is in such an atmosphere that those delivering the care operate within one habitus, and most of those receiving the care in another. For Mary, Rose and Yvonne, all mothers of seriously ill children, there was constant anxiety and unease created by practices and dispositions that seemed distant and cold to them. It could be argued that for those parents, the medical habitus was a challenging one where their role as parents became secondary to the medical role.

Facing the challenges to the parental role

A key parental role is to equip their children with the dispositions of manner as well as thought which will ensure that they are able to succeed within the educational system which will enable them to later reproduce their parents' class position in the wider social system (Bourdieu, 1984). Other parental attributes, such as caring for children, serving their needs, controlling their behaviours, and tending to them when ill, are viewed as a normal part of the parental role. This is especially so when such behaviours serve to reinforce social behaviour and responsibility in the form of cultural habitus. However, all parental thoughts of the future, and all notions of the child's role in society are severely threatened by a sudden and serious illness. The parental role in these circumstances is therefore affected considerably when there is a perceived loss of control to clinical staff:

And at home feel like you're the parent again, and you have some control and you have a role in this child's life. But as soon as you go back to the hospital it's just dreadful, you no longer are of any relevance and no longer feel that you're - there's no privacy (Mary).

In the hospital setting, where the dominant culture is that of medicine, parents may seek confirmation of their role from the closest societal group like themselves, i.e. other parents (through a more neutral set of discourses) but this too can prove difficult and equally distressing:

In the beginning I took notice of other families and what was happening for them and engaged in conversation and was gutted every time. And then over time I became very withdrawn I guess, and couldn't deal with other people's grief - you know, it was too hard. So you put up these boundaries. I know a lot of other parents got into niches and you know its difficult. Its like human nature isn't it - you know, they got into their whole stuff thing and they winge and bitch and make

friends with one another and so on, but to this day I don't actually have any friends that I've maintained from that experience (Mary).

In the face of adversity, parents are treated in the medical world in ways that reduce their perceived capacity to be complete parents (Young et al., 2002). In this world, parental identity and role expectations are subsumed or modified by the medical team (Darbyshire, 1994). Sometimes the challenge to the normal parenting and/or the shared interfamily role of caring is remarkably blunt:

And when my mother in law went to see him, a nurse turned around to her and just said, "we're just leaving him to die". And I thought, "you – you – you know, you had no right to say that" (Rose).

At other times the challenges are more subtle and considered, but with a concealed purpose:

I recall being regularly counselled to frame my discussions with Jane in a realistic light, (I particularly recall this taking place in the treatment room amidst one dreadful ordeal or another). In actual fact from the beginning to the end of the three and a half year involvement that I had with the Oncology Department all this served to do was undermine any hope we had of beating the disease (Mary).

Such counselling was designed to modify Mary's initial optimism and hope for the future towards a more realistic acceptance of the situation, but in effect, it produced a "conscious and permanent visibility" (Foucault, 1977, p.197) through an act of surveillance that was aimed at role manipulation. Whilst this effect is intended to be subtle, it was noticeable by Mary, and caused deep resentment. In effect, Mary was positioned as 'unrealistic' by the medical professionals working with her child; but she resisted their positioning and adopted an alternative narrative based on hope and an imagined future:

I think it is important that nursing staff be aware of the families need to believe whole-heartedly that their child can survive, irrespective of how things turn out. Hope is more than blissful ignorance or a state of delusion; it has an essential role in well-being and potential recovery - despite how greatly the odds are stacked against survival. If the child dies then a parent has no choice than to live with the outcome, and in this event a reality check is inevitable. Let the parent come to terms with that when and if it happens, and otherwise allow them hope unto the very end. Then they will not have to come to terms with the fact that they gave up on the child. Imagine how it must feel to be a wee kid, fighting with all the awesome and innate strength of the will to live, when every adult around you is pessimistic and "realistic" about your chances - including your parents. You can't tell me that this doesn't have an incisive impact on the child's psyche (Mary).

For Rose, who was a mother *and* a nurse, these dual roles sometimes caused internal and external confusion. For instance, Rose was expected to play 'the parent role' in the hospital (i.e. the role assigned to parents by medical staff), but was also fully aware of the impact of her other role as a nurse, which at times, caused a degree of role confusion for the nursing staff (i.e. she was a parent and 'one of their own' at the same time):

...some of them were student nurses and some of them knew who I was by that stage, and it must have, I don't know if it had in red [in the notes] "Mother's a nurse", but it was like "back off Mum" or "Mum's there" type thing so that was...and there was a little bit of...yeah (Rose).

Overall, her role as a parent and a nurse working at the same hospital where her son was a patient) meant that even she expected slightly different responses from the health care team that she personally knew. To her dismay, she received very little support from them:

And I suppose the other thing that did annoy me on a personal note is that I was working with a group of disability house specialists - that was my field of work. I asked some of my physiotherapy colleagues if there was any passive exercises I could do and they gave me no help. I talked to my social work colleague who just blew it off and they didn't seem to acknowledge the stress that I was under personally at work. And they didn't make it their business to know what was going on with Nigel although I was perfectly open and he actually had to go to clinics where I was working, so when I was bringing him to clinics, and that, I found...I thought as health professionals go, their lack of support was appalling (Rose).

Clearly, for Rose, her attempts to position herself as both a parent of a seriously ill child and as a health professional were largely resisted by her colleagues. This resistance is based upon the notion that at work, a 'professional self' is required, and ways of communicating within personal relationships are subdued. Rose encountered the difference between providing care within nursing and providing relational care as a parent; subsequently, she is offended by the seeming indifference of her colleagues. Nevertheless, in the challenges to Mary's, Ann's, Rose's and Yvonne's roles as parents within the hospital environment, it is apparent that each one not only perceived the challenge to be a threat to their role, but to their identities.

The challenge to parental identity

In a Bourdieusian analysis, physicians belong to a certain type of social class (i.e. 'medicine', 'professionals' and 'experts') but parents that find themselves within the health care system are another type of class (i.e. 'health consumers', 'amateurs' and 'novices'). As the recipients of medical expertise, parents are expected to respond in ways that reflect the status and prestige of the expert class, and therefore permit themselves to be subjugated or constrained by medical representatives when 'in their care' (Frank, 1999). As some parents belong to the 'expert' or professional classes themselves, this presents a challenge in the perceived identity by which they may be identified. Nevertheless, parents that group together in resistance may transcend common notions of social class at times because of a stronger allegiance to the group. In such cases, identity and not class is capable of overriding class distinctions, at least for a while.

For Foucault (1977, 1979), identity was a 'cultural construction' constituted in discourses that occur between people as they interact with others. Identity is a constantly shifting, temporary construction that may have to be reasserted in the face of challenges from others. Identities are crafted, modified or abandoned, and particular courses of action are followed, according to how people are located by others and by themselves, however temporarily, within a range of discourses (Phibbs, 2001). Identities are never complete, but are always in the process of being formed or changed. Subsequent actions that are reflective of changed identity produce new discourses, and hence new politics and new communities of interest (such as concerned parents groups). Bourdieu (1984) maintains that class mobilisation in the form of collective action tends to occur when factors arise within a specific context that represent a threat or interferes with the 'normal' functioning of the class. Resistance could therefore lead to the

formulation of new alliances that parents sometimes mobilise by forming cliques within the hospital (as Mary previously identified) but not necessarily as a large collective group.

If Foucault's position on individual identity within relationships is also taken into account, then the possibility of a parent or parents offering resistance to desired medical advice will always remain regardless of whether or not those parents perceive themselves as members of a particular social group or field. Thus, individuals may offer resistance as autonomous beings within a structured set of institutional practices (such as including alternative therapies as part of their response to those practices) and at the same time may actively or passively encourage others of like mind (or habitus) to do the same. In doing so, such individuals may take on the mantle of an altered or changed identity. Hence, within an institution such as a hospital, parents will be positioned in regard to their role and identity as the immediate carers of the child, but not normally positioned as expert carers. Conversely, resisting parents may be positioned as 'irresponsible', or 'difficult' or even 'malicious' under certain circumstances, but differently in other circumstances.

Returning to the parental narratives gathered for this thesis, it is now possible to reconsider parental identity in light of the previous discussion. It has been maintained previously that parents like Mary, Ann, Yvonne and Rose attempt to perform the dual role of 'being a carer, being a parent' (Young et al., 2002) whilst in hospital with their sick child, but their roles are affected and re-fabricated by both personal factors (dealing with anxiety and grief) and interpersonal factors (dealing with clinical staff). Their identities, as mothers, carers and their children's spokespersons, are therefore reshaped by circumstance. It is hard to be one thing and another at the same time. For instance, in Mary's case, as she continued to attempt to adjust and reassert her identity as a mother of a child with cancer, she was shrouded by constant uncertainties and fears including at one point, the following devastating information:

[They told me] that if she relapsed, she would more than likely relapse within 12 months and would die. So, yeah, even then going into remission was not a foregone conclusion; even after the 12 months of massive doses of chemo she may or may not go into remission, so of course it's that roller coaster isn't it?

Thus, the 'roller coaster' that was medical-surgical treatment went on with Mary largely as a bystander, her parental identity and role severely challenged by the fact that she could not more fully contribute during times of medical crisis. In effect, she was more or less forced to stand aside as her child was placed into the hands of the medical team.

One aspect of parental identity that remains when others are modified is the core identity of familial and personal connection. Yet, for parents such as Yvonne, after all possible hope seemed to be extinguished for her, and when faced with an indefinite future of extensive daily care for her ailing son, even this fundamental identity can be challenged by biomedical pressure to modify the parental role. She found herself one day in the middle of a conversation with physicians about the possibility of 'assisting her son' towards an easier death:

They actually discussed it with us, paediatricians even! I'm not saying who did it, but X even told us exactly what to do, and I turned around to X and said, "How can you tell me to overdose my child?" When what is the right amount of morphine to give him, you know, he's on that much already?' And I said to them: "Being a mum, I can't do it." (Yvonne).

'Being a mum' or 'being a father' in relationship with their child/ren is a 'bottom-line' for most parents. In situations involving a serious illness affecting one of their children, all of the parents in this study fought hard to maintain this identity at all times, even when pressured to conform and agree to an act that did not sit well with them. Hence, some parents will find ways to conform to medical desires that they dislike (usually because they have been convinced that their agreement is in the best interests of the child), and other parents will find ways to resist.

The development of parental resistance

According to Foucault (1977), the type of power that exists within and between those who represent use an institution (such as physicians in a hospital) and those who use it (such as parents and their children), will always produce a potential for resistance in a variety of ways. Attempts to maintain agency through preserving their identities as parents in the relationships with physicians contains such potential. It will now be argued that when identities are threatened, or relational tensions emerge (Carnevale, 2005), several of the discursive incidents already noted contain 'seeds of resistance'; and that these elements emerge through the daily schedules and programmes of human interaction in what is considered to be a rational, logical and objective setting. In this thesis, the main themes that predispose parental resistance are 'loss of faith', loss of trust', 'loss of hope', the 'diminishment of altruism' and/or 'loss of respect'.¹⁰² When such elements enter into the relationship between parents and the medical team, they are described in this thesis as 'tipping points.' These elements are seen as 'seeds of resistance' which lead to both covert and overt responses. Both the development and emergence of parental resistance are now elucidated by the use of analytical examples from different parents' stories.

The predisposing elements of parental resistance

Loss of faith

Excerpts from Rose's narrative have been chosen to illustrate the gradual emergence of parental loss of faith in physicians, and therefore the planting of one of the 'seeds' of parental resistance. After her son's initial onset of illness, he was admitted to hospital where a bevy of medical

¹⁰² A similar set of elements were found by Carnevale (2005) in his exploration of disagreements between the parents of critically ill children and physicians. He concluded that "the clinical encounter on pediatric care can give rise to relational tensions (over respect, trust and power) rooted in the disparity of moral horizons among the persons involved" (p.249).

consultants were engaged in finding a physical reason for his symptoms. She described her experiences when dealing with the physicians in the hospital:

...we've got a really strong [X] dysfunction history in our family, particularly the maternal side. Every member of the family, including me, has had some [X] dysfunction at some stage and I explained that to I don't know how many doctors in the early stages. So, when they said, "anything in the family?" [I said] "Yes, [X]!" So they all knew it, and they all wrote it down, and I actually did a graph for it at one stage, and, you know, marked the little dots on who was affected and who wasn't.... But it was like pushed to a side really; that it didn't seem to quite fit, and we were reasonably satisfied with the fact of, OK, they've found this [another disease], we've looked it up on the internet and the way Nigel was presenting seemed consistent with that (Rose).

The medical disinterest in her idea, and the lack of an adequate response, clearly irritated her, especially when later she was proved correct in suggesting a diagnosis that was based upon her knowledge of the family history:

...So it was captured, but it was never acted on. And I found out some time later, when I actually got to what Nigel's diagnosis actually was that they had never ever done a [X] function test at that point. So they'd done other things, but they'd never tested for his [X] function (Rose).

Rose became annoyed by what she perceived as the constant and inexplicable lack of logic and objectivity that prevented the assembled physicians from performing a relatively simple test that would have identified her son's condition. That numerous physicians chose to ignore her advice concerning her own family's health history illustrates a medical inability to entertain any other source of diagnostic information other than their own. In short, it is a form of symbolic violence; the physicians' field had been entered by a parent, and they were not interested in accommodating her as an expert. It also marks the point where she started to lose faith in nearly all of the physicians caring for her son, and began to find ways to resist the proposed diagnosis and treatment. As a nurse and someone very familiar with her family history, she chose to use rationality and objectivity to restate her case, but this was unacceptable to the physicians, their own logic prevailing. The lead medical consultant resisted Rose's constant questioning of the validity of his diagnosis, and responded as if it were a direct challenge to his role, and therefore his identity. Furthermore, when Rose's suggestion was dismissed by the medical consultant in favour of his own alternative explanation to her possible diagnosis was dismissed by the rest of the medical staff as well, and they persisted with the original diagnosis telling her, "*Oh well, we're terribly sorry, neurological condition, he's going to have to make a life of it.*" (Rose). The dismissal of Rose's diagnosis continued after her son was discharged home, and when she took him to the family GP after yet another relapse, he was also disinterested with her ideas, and supported the medical consultant's original, but erroneous, diagnosis:

Well, we were getting very concerned because he was also losing weight and we had been going to the same GP since we had lived in Auckland. And I started to really lose faith in this guy because I didn't feel that he was really particularly interested in looking past what the consultant [who had also misdiagnosed Nigel's condition] had said. Like, "this is his diagnosis, this is what we're working with"; and that was all he could really see. (Rose).

This encounter damaged her faith in her family physician, and in the absence of a satisfactory response, Rose tried an alternative solution. She went for a medical opinion from another GP, and used that opinion to get her son back into hospital:

And the new GP was concerned ...and I thought: "Right, he needs to be admitted to hospital, this is obviously not good." And he was again admitted under the neurology team and again they were saying, "No there's nothing, we don't know what's wrong with him, we're satisfied with our diagnosis." But the GP by this stage had expressed, at least it would seem to the consultant that he felt there was something going on with his [X] function. And when he looked at it and you put all of the signs together – he had the weight loss, he had the anxiety, he had the sleeplessness, and he had the tremour... And when they did his [X] functions he was so hyper[X], it was just off the end of the scale (Rose).

After a lengthy struggle, Rose finally got an accurate diagnosis at the hospital; it concurred with her original suggestion as to the cause of her son's illness. In Rose's story, the damage done to her faith and confidence in the skills of the attending physicians by their seemingly stubborn refusal to accept her opinion, as a mother *and* as a nurse, was palpable. As Young et al. (2002) maintain, the quality of communication, information provision and relationships with staff all contribute in a crucial way to supporting parents as they seek to fulfil their role. Young et al. also note however, that:

Occasional lapses in communication were reported by some [parents], which usually entailed treatments being administered or changed without parents' knowledge. This was something that mothers found particularly upsetting, pointing out that it made them feel undermined or threatened (p. 1842).

In Rose's case, it was not just a matter of loss of faith in the skills of physicians to correctly diagnose a health problem in the child, but also problems relating to the maintenance of good medical communications with parents as treatment commences. When communication breaks down, or is minimized, a parent's trust in medical professionals may falter.

Loss of trust

Mary's narrative offered numerous examples of her gradual loss of trust in the clinical staff at the hospital based on the circumstances in which the diagnosis of her child's condition was made, and also on the daily incidents in her dealings with medical staff as treatment progressed. Her trust in clinical staff began to diminish when, over a period of time, she noticed that her input as the child's parent was being either ignored or dismissed. This caused resentment, and with it, a feeling that the staff were not trusting her to fulfil her role as a parent. She felt increasingly like a bystander, and increasingly like a nuisance to them (she felt like "emotional baggage", she was "dismissed a lot" – see p. 151). These feelings eventually became translated as personal insults and her trust in the clinical staff was affected.

However, this aspect of Mary's daughter's care alone was not the major cause of her loss of trust in the clinical staff, but it did set the tone of her relationships with the staff. In her case, as occurred to Rose in the previous discussion, the seeds of resistance were sown by a number of interrelated incidents where Mary's power as a parent was challenged and suppressed in favour of the physicians or the nurses' use of medical biopower. There were three major incidents that

caused this, the ‘catheterisation incident’ (where mistakes were made by the clinical staff that had caused her daughter unnecessary stress and pain), the ‘Hickman line incident’ (where staff incompetence had led to the failure of the line and the need to remove it – which caused more unnecessary stress for Jane)¹⁰³, and a final incidence where it seemed to Mary that her child was no more than an interesting case for clinical experimentation:

After 22 months she relapsed and then they said - actually this one really pissed me off - they said, “You can leave her and she’ll die within 2 or 3 months or you can put her in a trial...” (Mary).

In this instance, the ultimate use of medical biopower is made utterly transparent. Even in the face of the imminent death of a child, and after months of experimentation with cytotoxic drugs in ever increasing doses, medicine offered yet more drugs, but this time, as an experiment, a last throw of the medical dice. It “pissed Mary off” because, as she went on to explain, her role as the child’s mother was reduced to that of an official decision maker without a great deal of choice, a ‘rubber stamp’ mechanism for the desires of the medical team. Nevertheless, such uses of medical trials, it has been maintained, are not necessarily just for medical (research) benefit; it is argued that there exists a significant degree of altruism and hope of a cure as well (Estlin, Cotterill, Pratt, Pearson & Bernstein, 2000). Mary subsequently accepted the trial and hoped for a miracle. Yet, such a hope is not scientifically well founded:

Although many respondents believed that children could benefit from medical improvement, feelings of altruism, and maintenance of hope, the chance of cure or complete remission was thought to be small. Similarly, parents were thought to potentially benefit through altruism and maintenance of hope....The main ethical concerns of respondents were risk of toxicity, consent of the child, unrealistic hope, and coercion (Estlin et al., 2000, p.1900)

Mary worried about the unrealistic outcome, and felt that she had been coerced because, as she maintained, she felt torn between this last miniscule chance and the imminent death of her child. In short, she was given an emotionally tactless but logically valid choice. In this way, her trust in the altruistic and humane aspects of medicine faded yet further. Nevertheless Mary, still desperate to give her daughter every chance, agreed to the trial, but was delivered yet another blow to her confidence in the medical staff shortly afterwards:

When Jane was put into the clinical trial in the last stages of her treatment we were shown the protocol and signed a consent form. However, only after her second dose of chemotherapy was administered (in a 6 stage programme), did I discover that they had not administered the same dosage or chemicals that we had consented to. They had changed the treatment programme without advising us in advance.

This third and subsequently final blow to her trust in the competencies of the medical team had a delayed effect, but culminated in her eventual refusal for any further treatment (radiotherapy was later offered) of any kind.

¹⁰³ Both of which are discussed in greater detail in later discussion in this chapter.

Mary's narrative offers further insights into the development of 'seeds of resistance'. Her gradual loss of trust in clinical staff is based on the assumption, as Foucault (1980b) maintains, that the presence of a type of logical and objective reasoning does not always equate to logical or adequate outcomes. For Mary, who frequently witnessed what was for her the distressing outcomes of an objective and logical medical approach to her daughter's care, the effect was to gradually erode her trust in the abilities of the clinical staff. Whether it is a gradual loss of faith, as occurred in Rose's case, or the development of mistrust (as in Mary's case), or both, parents that are ignored, or pushed aside, or treated as merely bystanders to a medical-scientific challenge will inevitably show some signs of resentment and/or resistance. If, over a period of time, such feelings are ignored, then parental responses may eventually exhibit more overt discomfort. For Mary, Foucault's prophetic observation: "At every moment the relationship of power may become a confrontation between two adversaries" (Foucault, 1982, p. 208) became a concrete reality.

Loss of hope, altruism and respect

Selected excerpts taken from Yvonne's story are now used to illustrate how parental loss of hope, medical altruism, and respect may lead to strategies of resistance. When the hopelessness of further medical treatment for a seriously ill child is obvious to both parents and physicians, parents seek expert palliative care from physicians and nurses (Kübler-Ross, 1969, 1997). Yet in practice, the parents' expectations are not always matched by the confidence that clinical staff will properly provide care for an acutely ill child in a fully caring way (Roden, 2005). In fact, the opposite may be the case, as in the following extract from Yvonne's story where hope and altruistic caring seem to be abandoned in favour of the quick and expedient death of her child:

...and we used to get our paediatrician from [X] saying, "just leave him in the room, just give him his medicines and shut the door. If he's alive in the morning, he's alive." And I said to him, "you can't say that." He said, "Then you go in there, and he's in such a state that you're going to have a really bad day just trying to sort him out." I said, "I can't do that, I'm his mum...It's easier for you to say it, you're a paediatrician, but this is my child, I can't." (Yvonne).

For Yvonne, hope, peace of mind and confidence in the physician is damaged in the above narrative, which clearly affected her sense of identity as a mother as much as her sense of altruistic decency. Yet, hope is a popular discourse in representations of people with cancer, or adults and children with life threatening illness (Kübler-Ross, 1969; Lupton, 1994a). It was the concept that drove Rose back to the physicians again and again until she found one that would respond in a fashion that she perceived as helpful. Hope fuelled Mary's need to press on accepting treatment after treatment for her daughter, but it was also the concept that finally defeated Mary as well. As an explanation for her negative feelings towards most of the health care providers that she encountered during the time of her daughter's illness, she said this:

In actual fact from the beginning to the end of the three and a half year involvement that I had with the Oncology Department all this served to do was undermine any hope we had of beating the disease (Mary).

In Yvonne's situation, because her child was diagnosed as a hopeless or 'futile case', it seemed to her that the quality of professional long term care became poorer or, as indicated in the following example, almost non-existent:

No, they used to just leave him. And only the times that were on their charts to go give him his medicines that they'd enter the room, otherwise they'd leave him. You'd go in there, and he had stuff coming out his nose, stuff filled in his mouth, because he could barely swallow. So he'd have a whole lot of secretions in his mouth because every seizure he had produced more secretions. So you'd have – I used to have to suction complete – sometimes I'd end up just standing there, suctioning constantly, of all the stuff, and it was just ridiculous (Yvonne).

Yvonne was frequently left to fend for herself, which included performing medical/nursing care such as suctioning. Yvonne's growing unease with her son's overall care cannot have been helped when later still she had an appointment in a large city hospital to review her child's situation. The possibility of some sort of treatment crossed her mind, and she was hopeful for anything when she took her child to the physician for assessment. However, it was not to be:

...but I had a disappointment one time when we actually got transferred over there by ambulance, just for the doctor to turn around to me and say, "the quality of the life of your child is very poor. We do not want to do anything." And I was very insulted and upset by that.

Yvonne was frequently offended by such incidents, which to her were summed up as a loss of respect, not just for her and her husband, but most especially, for her child. Nevertheless, Yvonne was not treated poorly by all health professionals in every institution she attended with her child. For instance, she found altruistic practices amongst the physicians and nurses of one large city hospital that cared for her child at an earlier stage:

I got the best care. I wished we'd gone to [X] in the first place. They were really neat to the children, the doctors and that were fabulous. ...They had reality, you know; they weren't, "oh, yeah, this is what's going to happen, this is what you want". It's like, "we're not in a dream, we're realistic. We know what's going to happen, we're not wanting to prolong it, we just want to keep him as comfortable as possible." Which meant pain relief for the poor little guy, bathing, you know – basic care for him (Yvonne).

This discourse does not offer Yvonne any hope, but it certainly speaks of the effects of altruism. If there is to be no hope, then at least the solace of charity and kindness clearly comforts distressed parents. But what if parental distress is ignored or dealt with in a casual, rather than a considerate fashion?

The emergence of parental resistance – the antagonism of strategies

Parents are 'reconstructed' as particular individuals within the medical system (as occurred for instance, in Mary's story); yet this reconstruction is a *product* of the use of one type of power, but not a reason for its existence. As Foucault argues:

There are no relations of power without resistances; the latter are all the more real and effective because they are formed right at the point where relations of power are exercised (Foucault 1980a, p.142).

Foucaultian resistance relies upon and grows out of the situation against which it struggles. Subsequently, such resistance may be muted in the ordinary circumstances of interactions between physicians and their patients. Nevertheless, there remains an increased possibility of

resistance when parents and members of the medical profession disagree over the medical treatment of a child. In this thesis, the more extreme clashes between these two forces have been called ‘radical parental resistance’; but, as has now been demonstrated, the none-radical struggles of Mary, Rose, or Yvonne indicate a pre-existing parental tendency to resist many forms of normalizing-disciplinary power that aims to restrict parents to a standardised role and identity within the medical system. Foucault suggested that such resistance may serve a useful purpose in society:

It consists of taking the forms of resistance against different forms of power as a starting point. To use another metaphor, it consists of using this resistance as a chemical catalyst so as to bring to light power relations, locate their position, and find out their point of application and the methods used. Rather than analysing power from the point of view of its internal rationality, it consists of analysing power relations through the antagonism of strategies... (1982, p. 208).

Resistance helps to pinpoint the use of power which, in a similar way to Bourdieu’s (1984) general position on the formation and purpose of societal fields, highlights those actions that structure the field, or provides the parameters for other actions within the field. In this sense, as Foucault noted, power becomes a mode of “action upon actions” and therefore its place within the social nexus is realised. In this thesis, the power relations between parents and physicians are of interest, and it has already been argued that within such relationships, there will be not only power relations, but also resistance to power *as a use of (resistive) power in itself*.

While it has been maintained that power resides within the medical realm, it also resides with parents. This is because “between a relationship of power and a strategy of struggle there is a reciprocal appeal, a perpetual linking and a perpetual reversal” (Foucault, 1982, p. 208). In this account, resistance is the deployment of alternative knowledges, and is subsequently a two-way system. The discursive themes now identified in this thesis – in the parent-clinical staff relationship, and the effects of medical actions (or inaction) – calls for some sort of parental response (or ‘action upon actions’ [Foucault, 1982]) to be taken. The interviews with parents suggested that parental resistance towards medical interventions was largely covert at the start, but became increasingly overt if the desired response was not forthcoming. Parents used *covert resistance* in the first instance because it was a form of resistance that was least likely to cause any major upheaval for the family or the physician whilst maintaining the best outcome for their children. These forms of resistance included resistive tactics such as ‘using the system’ and ‘playing the part’.

Using the system and playing the part

For Yvonne, using the system and playing her part was the maximum level of her resistance towards the medical system. It emerged out of a growing realisation that medical efforts to control her child’s seizures were limited, and that there appeared to be little else that medicine could offer. She had endured sufficient setbacks and disappointments within the medical system by this time, i.e. the change without notice of her obstetrician, being ordered around, the

rudeness and the inconsiderate ways in which the clinical staff had assessed, diagnosed and (to her) “*written off*” her child:

He ended up having well over a hundred seizures in twenty four hours, and the nurses had no knowledge of him having that many seizures, because we watched him like anything. And we were quite shocked when they said, “OK, we’ll try next week for you to take him home’. We took him home and they fully expected us to bring him back dead Yvonne).

In actuality, her child was simply discharged when it was decided no further institutionalised medical treatment was possible, and Yvonne felt that she was left with no choice. Nevertheless, in the uneasy periods that she nursed her child at home, she still maintained contact with the hospital, and used the facility when necessary. She also made use of three days respite care per month at the local hospice and welcomed visits from the local Public Health Nurse. At other times, Yvonne endured the difficulties of nursing her seriously ill son at home, where she became proficient at administering his complicated medication regime, seeking her own support networks, and coping with the stress:

Like, I used to draw up the medicines and I would end up having a tray of medicines being brought into him and there were about fifteen different syringes of stuff. His godmother ...was really supportive, no matter - even if there was a meeting at Y Centre and she wasn’t working, she’d come in on her day off just to be there for me, and that. ...you’d end up giving all the medicine to him and you’d even say to him sometimes, “why are you doing this?” You know,” it’s OK to release”, but he wouldn’t (Yvonne).

In the absence of any further medical care, Yvonne explored alternative systems of health care, and eventually sought out an osteopath:

We said, you know, “look we want to try anything possible, and we know cranial massage can sometimes reverse things that have gone wrong in the head.” He did it, and he was shaking his head the whole entire time and virtually in tears. He said it was something...that was very irreversible. We took him a few times to have cranial massage but it didn’t really help. It ended up making him fit more (Yvonne).

Eventually, when her son was five months old, Yvonne discovered that she could receive assistance from a local centre for children with disabilities, and she took him there once or twice a week to be cared for. After a period of several months of caring for him in such a way, her son eventually died.

Rose’s response to loss of faith, hope and trust in the consultant caring for her child (“*there was more that could have been done that wasn’t done at that time ...*”) was to avoid direct confrontation with the medical consultant who was causing her considerable angst, and to tackle the problem via an alternative route. This route was to pit one physician against another and Rose ‘lobbied’ two other physicians, a Specialist Consultant in the field that she suspected was an appropriate one for further medical investigation, and her new GP. Armed with a different opinion from the new GP, Rose took Nigel back to the hospital and her covert resistance became overt:

...and I guess it was certainly in terms of a turning point, that admission where I spat the dummy and said, you will admit him and you will look for something else, and the GP had also supported, and “you will look for something else” (Rose).

Hence, Rose may have felt 'helpless to make a change' initially, but was not entirely helpless to resist; and in the absence of any suitable mechanism to more directly challenge the status quo, she chose to resist by going to another physician who would listen to her argument, and then returned to challenge the consultant/system yet again from a more concerted and medically supported position. In short, she was silenced in the first instance, but got results when another physician (the new GP) agreed to advocate on her behalf.

Other parents interviewed for this thesis found ways to resist that were similarly guarded in the early stages, but considerably more overt in later stages, usually when they perceived the health or welfare of their child to be deteriorating to an unacceptable level. In Mary's story, which is characterised by a similar tale of slowly mounting resentment and resistance, the timing and degree of her resistance came after a considerable period of tension marked by a transition from full compliance to medical wishes and beginning resistive manoeuvres that were slight, hesitant, and largely a matter of playing the part of the ignorant and compliant parent for the (expert) consultants:

...and so then we went through this interview and I asked what I knew they thought were stupid questions. They said that she was going to die, although she was in remission it wouldn't hold; it would only be a matter of a few months before she relapsed and died ... we were very careful not to jeopardise her treatment not to rub them up the wrong way (Mary).

The degree of challenge to the physician/s offered by the parent was always tempered by anxiety that too much resistance might lead to a backlash, or a type of medical resistance. In Mary's case, there was no alternative medical opinion to back up her stance. Instead, she "*asked stupid questions*" and tried not to "*rub them up the wrong way*" in an attempt to get the best treatment and care for her daughter. For her, it was not so much active resistance as a brooding resistance that would only show itself later. Such is the power of the medical system, and the feeling of powerlessness for some parents within that system. Nevertheless, what happens to parents when minor resistive behaviour achieves very little towards what parents perceive as adequate medical responsiveness and/or care for their child?

In the face of negative perceptions about the physicians, or quality of treatment received by themselves and their child, some parents will go beyond covert or simmering resistance and engage in more active forms. It should be noted that this type of resistance does not usually emerge in earlier stages of parent-medical relationships, although (as was apparent in some of the five media cases discussed in Chapter Four) there are exceptions.¹⁰⁴ Nevertheless, when more active or overt resistance does occur, it is usually because of the gradual development of

¹⁰⁴ There are those parents who will resist almost immediately a doctor expresses a wish to treat their child. These more radical cases exhibit some similarities to the parents stories being discussed in this chapter, but there are considerable differences also (see Chapter One).

the predisposing elements, such as loss of faith or trust, or more specifically, the culmination of these elements. The ‘tipping points’ differ from parent to parent, but the end result is resistance in all cases. Active resistance starts when parents refuse to allow events to continue as they are. In short, a decision is made by some parents, either as a predetermined or spontaneous act, to ‘stand their ground’.¹⁰⁵

Standing ground

Rose’s and Mary’s commentaries provide good examples of parents ‘standing ground’. The catalyst for Rose, who was both a parent and a nurse, occurred when the specialist physician refused to entertain to her request for further tests. For her, the biggest battle was to get a satisfactory medical response from this physician who, for reasons that may well include personal pride and/or the preservation of medical reputation, exhibited denial, aggression and symbolic violence to make his point:

Like he was really aggressive and not very pleasant and I haven’t quite forgiven him for that, and it was that [specialist consultant] who said “basically it’s in his head, he needs a psych consult, there’s nothing neurologically wrong with this boy. He needs to get up and walk. He needs to get rid of that wheel chair, take it away right now”. And he physically took the wheel chair away, and I said, “well, it’s actually our own wheel chair thanks very much” (Rose).

Claiming ownership of the wheelchair may be interpreted as a symbolic gesture of resistance on Rose’s behalf, but it was a beginning or another ‘seed’. At a later time, both parent and son were back at the hospital seeking the consultant yet again:

...when he arrived at hospital, they said his consultant was away for the weekend, and I was furious. I said, “I don’t care if his consultant is away, you will put him under a general paediatrician, you will look for something different because what you’re looking at is not right. This kid is going to die and you are doing nothing about it (Rose).

This more direct challenge to the medical system (which was armed by a counter-opinion from the new GP) appeared to have an effect. Rose’s son was admitted, and his case was reviewed again, but this time by three specialist consultants at the same time. Whatever Rose had done, she had forced the issue for the physicians, who did not prevaricate any further:

The three of them [consultants] ...called me into a meeting. And at that point he (Nigel) was still an inpatient. That was the day that changed things ...I felt quite threatened – but I also felt – “I’m quite articulate and I’m quite prepared to challenge” (Rose).

Rose’s stood her ground and finally got what she had wanted long ago, a blood test that revealed that her diagnosis, based on her own expert knowledge of her own extended family’s health history, and her observations of the progress of her own son’s illness, was actually the correct one.

¹⁰⁵ In the radical actions of the parents in the five cases (Chapter One), there were resistive ‘tipping points’ too. However, active resistance was present right at the start of any form of medical consultation for some of these parents (as occurred in the Moorhead case, for instance).

For Mary too, the situation concerning her relationship with those responsible for her child's medical treatment reached a point where she decided to seize control over the fate of her own child and 'stand her ground':

I wanted to stand my ground and feel my feet firmly on the floor, and be present and be able to take whatever they were saying to me - I distinctly recall when she relapsed the second time and...we were on death row then, and I stood there and took it. I absolutely...found new strength, three years later or something. And I wanted to know the details, I wanted to know the facts, I didn't have the luxury, I didn't want to stand there and cry or do all those things and be dismissed, I wanted as much information as I could get from them so that I could make a decision fully informed about what we going to do (Mary).

To do so, as it can be seen, she decided to 'know all the details', ask many questions that she had not asked before, be unemotional (which she associated with medical objectivity) and seize back a modicum of parental control that she thought she had lost. Mary provides her reasons for her decision to more actively resist in this excerpt:

And so yeah, we decided at that point we weren't going to do it. We didn't have our next interview with our usual oncologist...and I remember this guy, I'd not seen him before but I'd heard a little bit about him, he was really horrible, he was really horrible. He sat there and said as much as you've made this choice to go your own way so the consequences will be on your head - you know (Mary).

Taking back control

Mary took back control of her daughter's destiny after lengthy but eventually ineffective treatment that included both the use of cytotoxic drugs and surgery. She later allowed her daughter to become part of a clinical trial that she felt very uneasy about, mainly because her trust in physicians was severely eroded by that time. Nevertheless, it was not until the family was sent to see radiotherapy specialists that she decide that she had had enough:

Okay, at the end of that treatment, they then sent us to the X institute ... where we had interviews with these two people ...and they said that she was going to die, [i.e.] although she was in remission it wouldn't hold; it would only be a matter of a few months before she relapsed and died. And so we had to give her radiation because that would keep her at bay for longer(Mary).

Mary wavered at this final, desolate offer from the medical profession, especially when told of the likely side effects the treatment would impose on Jane, and perhaps for the first time for Mary, the uncertainty about whether or not she should accept the treatment on behalf of her child grew as the situation developed:

...there was a little bit of hesitation on my part, you know, they could tell. We said: "We want to think about this. We're not really 100%", but we're very sort of agreeing so, as to say, they measured her up and all the rest and I think they were quite convinced that we were more than likely going along with it (Mary).

However, Mary was now perhaps for the first time hesitant, and also perhaps for the first time since the start of the many difficult and unpleasant treatments that she had seen Jane undergo, finally decided as a parent that enough was enough, and took control; at first rather hesitantly, but then with increasing confidence:

We were saying our goodbyes and he had the form there and he wanted me to sign it and I said, "no, I wasn't ready to" ...and then I asked him things about the doses that he was going to give her and I asked him technical questions, and you could see his whole personality changed instantly. That I was going into his area; that I wasn't some dumb parent going along for the ride ...(Mary).

The effect of a parent hesitating and then questioning the physician was as noticeable as Mary's conclusion that suddenly, she was actually resisting medical advice. The physician became annoyed:

... and there was a real sort of resistance there - not imagined - it was real - I thought something's not right with all this. I went through it quite open mindedly but knew that something wasn't right and then, yeah, we decided at that point to look into all the alternative stuff and it was the first time I'd ever bloody done it ... And so yeah, we decided at that point we weren't going to do it (Mary).

For Mary, the locus of control changed when she decided to resist any further treatment. As she saw it, her child faced likelihood that far more pain and suffering if she accepted the offer of more treatment, and so she refused any further interventions in favour of achieving optimum quality of life for her daughter. In her decision, which was based on the best interests of her terminally ill child, it could be expected that both parent and physician would see eye to eye, but this was not the case. In fact, there was now resistance and annoyance from oncologist as well.

Mary thought that she knew the reason:

[Mary] They wanted her in the hospital. [Interviewer] *For what purpose?*

It's control. Its them having - they have - its that thing of them not wanting to be examined too closely, I believe. Because [in the hospital] they've got the whole full control on it, they can basically - I mean the nurses that are running that unit have been there for 20 years plus, so they've got some ideas that they have huge impact on the new nursing staff coming in (Mary).

In short, Mary perceived that 'they' wanted the family back into their own field of control, where parental resistance is naturally diminished, and control easier. As this did not happen, Mary expected the expertise of the medical unit to leave the confines of the hospital and come to her, but this did not occur: "*So you were on your own. If you didn't follow the medical model you were on your own. There's no money, there's no support, there's nothing. Just crap*" (Mary). Mary's journey had gone full circle and, in a fashion, her resistive manoeuvres had been met by equally resistive responses from the physician. That is, from being a parent with a socially recognised and sanctioned identity (constructed as it were within a medical field that expected her to respond in ways that would protect and speak on behalf of her own child); to being a frightened witness of her own child's struggles within a different and alien field, where the cultural capital of medical representatives predominated, and where her own ways of exercising her beliefs and values was suppressed for the greater good of her child; to the final decision to reclaim her own child, and her own identity as the child's decision maker.

Maintaining control

Mary chose instead a type of resigned acceptance of the inevitability of it all and refused any further medical treatment in favour of her own interpretation of a suitable alternative treatment

(fruit and vegetable juices), and both parent and child benefited enormously from being back within their own environment¹⁰⁶:

She lived 6 months, and I thought, I'm into juicing and did all sorts of things. She was in fine form, the house was full of giggles and in the end she went back to school and we had a wonderful last 6 months - it was great. And yeah, sure she relapsed and died within 3 weeks (Mary).

As maybe expected, Jane's inevitable demise was a trial, but it was made easier because of one key element that Mary identified several times – parental control within a familiar environment:

We got support from some religious care place and that was great. Had everyone around her at home - it was great. Her dying was really... [Inaudible] ...within our control. The GP that assisted us didn't have experience with children and so she didn't have a need to consult with the hospital with the department, you know, the cancer unit, but she was great. And for the first time in the whole bloody business we felt like we had some hand in it and some say in it (Mary).

Nevertheless, within her own environment, any other representatives of the medical profession, such as the general practitioner, became visitors to her world, and within her sphere of control. This situation was quite different from the previous one, whereby Mary was subjugated to the hospital routine in which the wishes of the medical team took precedence. In Mary's world, things were different. She got enough support from her GP and 'a religious care organisation', and perhaps for the first time since her child became ill, she felt she had control over her daughter's care. Thus, Mary's resistance became not just a localised and temporary one, but a longer lasting one like that of Yvonne and Rose; for Mary, as for them too, it would shape all further contact with medical professionals should she need care for herself or her family in the future.

Summary

This chapter has presented an analysis of parental resistance from the perspective of the parents interviewed for this thesis. Within the parent-medicine relationship, it has been shown that there are several themes at play, such as medical habitus and field, symbolic capital and violence, and challenges for parents concerning both their perceived roles and identities within the medical system. It has also been demonstrated that, for some parents, such discursive elements create an atmosphere of unease and anxiety for them that may then be 'tipped' or further exacerbated by any incident within the medical environment that damages the parents' faith, trust, or hope within the medical system. Should this occur, then it has been argued, the chances of some sort of emergence of parental resistance are greatly increased.

Mary's resistance, and the other examples of resistance offered by the other parents discussed in this Chapter, had less of a public impact than the types of radical resistance

¹⁰⁶ Which is recognized as a major benefit by other parents facing similar a predicament (Darnill & Gamage, 2006).

reported in the media that was noted in earlier cases (such as the five 'radical' cases outlined in Chapter One and discussed in greater depth in Chapters Four and Five). Nevertheless, it was a type of resistance that clearly grew from her interactions with medical personnel, which, on each new occasion, and especially as her daughter's prognosis and life expectancy deteriorated further and further, tended to aggregate over time in ever increasing amounts. This type of resistance, a slowly emerging and experiential one, is as formidable and as powerful as the related but seemingly more radical types noted earlier in this thesis. As noted previously (page 180), resistance is a 'chemical catalyst' that illuminates power relations and to illustrate how they operate within an antagonism of strategies that are as available to parents as much as they are to clinical staff.

Like other forms of resistance, parental resistance that is once established may not dissipate easily; indeed, it may become a more permanent discourse, as it did for Mary and for the other parents who encountered similar themes in their relationships with members of the medical profession. It is also likely that if the same parents, or other parents who have encountered the institutionalised medical system because of serious childhood illness, ever have to use medical facilities again in the future, a type of pre-existing resistance of heightened intensity will already be a part of their unconscious *and* conscious responses. This system could therefore be a self-perpetuating and circular one that heavily depends on the demeanour and actions of the medical staff that respond to parental requests for medical help. It is vital therefore, to study the responses of medical staff in greater detail in the next chapter.

CHAPTER SEVEN

Communication, negotiation and compromise: Exploring physicians' talk about parental resistance

Thus all the symbolic strategies through which agents aim to impose their vision of the divisions of the social world and of their position in that world can be located between two extremes: the insult, that 'idios logos' through which an ordinary individual attempts to impose his point of view by taking the risk that a reciprocal insult may ensue, and the *official naming, a symbolic act of imposition which has on its side all the strength of the collective, of the consensus, of common sense, because it is performed by a delegated agent of the state, that is, the holder of the monopoly of legitimate symbolic violence* (Bourdieu, 1991, p. 239, italics added).

Introduction

In this, the first of two chapters to examine the discourses of members of the 'clinical team', the emphasis is on the relationship between physicians - who primarily represent an institutionalised response to illness as delegated agents of the State - and the parents of a seriously ill child. The chapter examines those relationships through the narratives of five physicians, and seeks to draw out their understandings and views about how to respond to parental resistance. In the case of medical perceptions of the causes of parental resistance, physicians identify religious or philosophically different belief systems, psychological factors, cultural differences and/or ignorance, neglect or abuse as the main causes. Their responses to parental resistance are encapsulated within three central themes; communication, negotiation and compromise. To theoretically represent these responses, the chapter is framed by selected analytical ideas on the cultural aspects of medicine provided by Lupton (1994a; 1996; 1997); and from Foucault's (1975) explanation of the development of medicine and the subsequent patterns of modern medical procedures, and to a lesser extent, from his arguments concerning the maintenance and uses of power (1977, 1982). Bourdieu's theory on class distinctions (1984) provides a sociological framework in this chapter, and his ideas on different forms of capital (1986) and the uses of disciplinary power (1988) are also incorporated to illustrate distinctions between the habitus of medicine and those of parents.

Lupton's work on the uses of power within the medical encounter is a post-modern response to a paradox of the modern age; with the rapid increase of technical and scientific developments within the western world comes an increasing level of social anxiety, distrust and deepening insecurity (Lupton, 1994a). As Foucault (1979) maintained, the current epoch features a proliferation of modernist discourses about subjects such as sex, behaviour, discipline, risk, desire and lifestyle that are predominantly presented as liberating; yet at the same time, these discourses only create even deeper and more insidious anxieties and repressions. As people turn

to the medical profession for advice in relation to the effects of the ever demanding and increasingly complicated socio-technological world that many now live in, there is a growing notion that medicine, and its capacity to cure, is a source of increasing disillusionment (Illich, 1977; Rose, 1992). Drawing upon the political economy viewpoint, Lupton argues that the basis of medical power is *not* necessarily the relationship between the (altruistic) provider/physician and the (grateful) recipient/public – which is by and large a functionalist perspective – but within the notion of competing interests, namely medicine is dominant within society because “power enables physicians to act in the competent role demanded of them by most patients, and which is legally and professionally prescribed” (1994, p. 118). Subsequently, Lupton’s (1994a) particular focus on why issues of health, illness and medicine are now “surrounded with controversy, conflict and emotion” (p. 2) provides the material to assist in an examination of the personal and social controversy and conflict that surrounds parental resistance to medical interventions.

The main arguments in this chapter are presented in three stages. The first is that the physicians who provided interviews for this study tended to suggest that parental resistance was largely a problem of communication. Their perceptions on the predisposing factors of parental resistance mirror few of the discursive features that emerged so strongly for the parents (as in the previous chapter), but do reflect established viewpoints found in medically related literature (Brody & Engelhardt, 1987; Cant & Sharma, 1996; Eisenberg, Kessler, van Rompay, Kaptchuk, Wilkey, Appel et al. 2001; Yeh, Lin, Tsai, Lai & Ku, 1999). The second argument is that these viewpoints colour the physicians’ responses to parental resistance, which begin with mild and accepting behaviours based on a degree of altruistic professional latitude. However when parental resistance does not abate or the physician perceives that their position as the leader of the medical response to a child’s serious illness is significantly challenged, varying degrees of paternalistic and controlling behaviours take over. It is these very behaviours that in the previous chapter on parents’ views, it was argued that the ‘seeds of resistance’ were planted. Thirdly, it is argued in this chapter that in some of their responses, physicians risk losing the trust of parents and allowing a resistive situation to veer ever closer towards legal solutions whenever any fundamental physician-parent impasse emerges that is improperly recognised and/or not dealt with in an effective fashion.

Doctors’ views on parental resistance

Lupton (1994a) maintains that because of the socializing process by which physicians obtain and maintain their official credentials to practice medicine, there is a distinct pattern of behaviour and responses. In turn, this pattern (or matrix) has a distinctive type of socially patterned preferences and propensities that constitute a habitus within the field of medicine that is both well established and maintained (Bourdieu & Wacquant, 1992). This long established

'tradition' involves a number of elements that Foucault (1975) identified as a particular collection of genealogically recognisable behaviours that culminate in an encounter between physician and patient that operates under a set of 'rules' within a 'game.' This phenomenon has been described as 'the professional game' that Maseide (1991) suggests is an institutionalised norm rather than an exception. The rules of the game are based upon both professional and legal foundations within society that permit the use of established medical interventions. This involves one party, the patient, permitting the necessary medical investigation according to the terms and conditions that are maintained by the physician rather than the patient (Frank, 1999). The patient is thereby expected to utilise the service in a proper fashion, receive the diagnosis - when it arrives - and respond with gratitude and a willingness to participate in the treatment that is offered. Such terms are nearly always driven by a number of factors such as the willingness of the physician to 'see' the patient, time constraints, the availability of appropriate technology, and by the medical need to process each 'case' as efficiently and objectively as possible. This necessitates the maintenance of a type of personal detachment and control which enables the practitioner to work unimpeded by any patient orientated processes that might detract from the task in hand. Thus, medical authority is maintained, and the use of such power and authority becomes an expectation of both parties. Subsequently, it may be argued that physicians are expected to behave in ways that are as much influenced by the medical field and habitus of practice as any other health care professional (Luke, 2003).

In some situations, the patient's guardians/parents do not recognise the 'field of power' that is medicine and act in opposition to the established 'rules.' This may occur when parents either refuse to accept 'the professional game' in the first place, or, once at the beginning of the game, question the rules and attempt to disrupt, subvert, or abandon them. These types of resistance have been shown in this thesis to vary considerably from an early (and radical) parental refusal of medical treatment, to the delayed kind that is exhibited by parents who accept treatment but then disrupt or subvert 'the rules' in ways that are less publicly visible. In this thesis, a type of 'established resistance' often appears when certain factors in the treatment regime do not meet the expected outcomes, or the parents turn against recommended treatment for reasons such as lack of trust or confidence in clinical staff (as discussed in the previous chapter).

As has been shown previously in this thesis, parental resistance may not only challenge individual members of the medical profession, but also the institutions of medicine, media, law and the family as well. This is because the established, professional and socially sanctioned 'game' of medicine (or its rules, or even the very components of the game itself) are challenged and threatened by such gestures. In light of the previous discussion on the perceived role of physicians in society, it is pertinent to explore the possible reasons for parental resistance offered by the physicians interviewed for this research. On analysis, their replies do not mirror the discourses offered by parents, but rather those that are offered from a discursive analysis of medical

and legal literature.¹⁰⁷ These discourses predominantly feature causes and responses of parental resistance to the medical treatment of children in the western world that reflect what Foucault (1982) referred to as a ‘system of differentiations’, whereby one individual or one group feels free to judge and act upon the actions of others because of medical tradition or law. Physicians operate from a higher form of social capital expressed as status or privilege (Bourdieu, 1984) which enables them to validate their judgements of ‘others’. Subsequently, the narratives of the interviewed physicians mirrored most of the more commonly offered arguments for parental resistance (as noted in Chapter Three, i.e. on religious grounds, distrust of the health care system/physicians/drug companies, different socio-cultural beliefs and values, psychological factors, and ignorance, neglect, and/or malice) from within *their own* social position. Their responses to parental resistance likewise illustrated a strong and entrenched belief in the ‘rightness’ of established forms of medical decision making based not on the perceived rights of parents, but on the rights of physicians to make clinical decisions from within an established (Foucault, 1975), socially and legally sanctioned position of authority (Foucault, 1977, 1982; Bourdieu, 1984, 1986).

Subsequently, both physicians and nurses perceive their role to assess the behaviour of resisting parents in relation to their own health care practices and to respond to that behaviour in ways which they perceive to be both appropriate and within their given roles.¹⁰⁸ The first step towards this role is to make some sort of judgement about parents who resist treatment for their child, and in the positivist and scientific traditions of medical diagnostic traditions, find a satisfactory cause for this behaviour and classify it. This type of differentiation between the norm and abnormal was apparent when the physicians’ interviews were examined, and four main discursive themes emerged from the physician’s perceptions of possible causes of parental resistance as offered during interview. They may be broadly categorised as ‘dissimilar belief systems’, ‘psychological factors’, ‘cultural differences’, and ‘ignorance or neglect’.

Religious or philosophically different belief systems (that are not ‘mainstream’)

This theme draws upon the notion of ‘otherness’¹⁰⁹ and reinforces the notion that there exists in the world a number of parents who do not fit into the expected norms of society, usually because they have chosen a path that is not ‘mainstream’, as one physician explains:

¹⁰⁷ As outlined in Chapter Three.

¹⁰⁸ As an example, there are physicians who refuse to treat patients who smoke cigarettes and present with, for instance, heart or lung disorders, on the grounds that they judge such people to be unworthy of medical care under the circumstances (Lupton, 1994a).

¹⁰⁹ See pages 97-99 in Chapter Four, and also pages 136-138 in Chapter Five.

Now nature may take its course and the child then dies so that's, if you like, one side of the ledger. The other side of the ledger is where the family want to stop treatment or don't want to pursue a particular treatment - the doctor wants it in the child's best interests - and that might be often for religious or philosophical opinions on the side of the family that are not perhaps main stream. They may want to pursue or not pursue a line of treatment which the doctor feels is not in the best interests of the family (D3, p.3-4.)

In the above instance, 'not being mainstream' is akin to being outside of societal norms. The physician perceives parental resistance as an abnormal parental reaction to what, in his eyes, is a 'normal' suggestion for medical treatment that is 'in the child's or the family's best interests' according to the medical (scientific) viewpoint. It is also an example of the link that is commonly made by physicians to the law and the right to intervene in the 'best interests' of the child regardless of the parents' viewpoint¹¹⁰ and regardless of what they may consider to be in their own overall best interests.

Physicians interviewed for this research are prepared to work with parents who they characterise as out of the mainstream if there are signs of parents attempting to communicate in a more open fashion with the medical team. In the following narrative, a physician talks about the parents of a child that had multiple life threatening complications after birth. He described the family as 'very, very religious' but maintained that he could work with that as long as there was adequate communication from the parents. In this instance, the parents had talked about their usually private belief systems:

...they had some pretty strong beliefs [but] it was good that they were fairly honest about some of their beliefs. And that this child's picture had been put on a website, and the family were praying for it, and people around the world were praying for it, and their feeling was that this baby would be cured by the power of prayer and all they had to do was just wait (D4, p. 2).

This pleased the physician because it reinforced his identity as a 'good' physician in as much as such parental 'confessions' (in the Foucaultian sense) are more acceptable, and therefore more indicative of compliance, than those parents who will not discuss their belief systems with the physician. In return, the physician encourages such a response by creating space for the parents, not closing the conversation down, and encouraging them to talk about their beliefs. Thus, the ability of parents to be 'honest' about private or personal spiritual values is viewed by this physician as a largely positive event:

A lot of people are honest about it, I think. It's not that it's more common, I think it's just we talk about it now. And I think that's good because people are being honest about what they believe and that, and feel comfortable enough to do that (D4, p.3)

On the other hand, if deeply religious parents take an incomprehensible approach to the need for medical interventions, and instead present a seemingly illogical and highly subjective stance in

¹¹⁰ See pages 77-79, Chapter Three.

the face of 'rational' argument, another interviewed physician suggested that they would eventually 'draw the line':

Well I mean there's, there are different belief systems, and you can understand people having different belief systems, but the medical system does as well. I mean you know all that's alive and well you know. People believe in the mystical...and have done from 2,000 years ago....So I can understand people believing that, but my job is to be an advocate for the child and ...that's my job; and I think in any situation where ...if you know that whatever has happened is causing harm to the child then you have a duty to do something about it (D5, p.5).

In this extract, the physician expresses understanding of the differing 'belief systems' (or symbolic capital) of others, and acknowledges that medicine is a belief system in itself, being a set of institutionally sanctioned ideas that are supported by state legislation. However, the excerpt also includes what might be seen as an 'unconscious' medical position on such differences based on habitus and doxa in as much as it is the perception of the physician that it is his/her duty to protect the rights of the child, and by doing so to also enforce medical discipline, to uphold the institution of medicine and its definitions of the rules of the game. The narrative also suggests that the physician's role and identity is implicated in offering a position on the belief systems of others as part of doing the job, or as a duty. In this regard, members of the medical field may be seen to be organising and legitimising the particular identities, practices and beliefs of others for a particular purpose (such as the medicalisation of social life). When it comes to the physician's perceptions about the need to act 'in the best interests' of a patient (such as a child), i.e. 'to do one's duty', then the best interests are nearly always going to be those interests that most closely resemble the dominant medical discourse.¹¹¹

Psychological factors

This theme appeared in nearly all of the interviewed physicians' texts, and was built on the notion that parents facing the effects of a serious illness that may kill their child will understandably be in a state of shock and grief. Therefore they may not be able to think clearly and objectively about important decisions (Glover, 2006); but this depends in part on the situation in which the parents find themselves, as one of the interviewed physicians maintained:

...and that to me is a real issue of grief, immense grief. And that will depend on whether it's an acute situation or a chronic situation. If it's acutely for example, road traffic accident - a child gets severely brain damaged - on a life support in intensive care, so the family are in denial and shock and the grieving process that a normal child 2 days ago; now they're being asked to make decisions about turning off life support, it's too overwhelming for the family... (D3, p3).

In this instance, the physician differentiates between acute and chronic cases, thereby making a temporal distinction based on time and circumstance. Parents who are faced with an acute episode are therefore forgiven for acting erratically because it is understandable in their

¹¹¹ As was argued for instance, in the Tribble case.

situation; but parents of children who are chronically ill are judged differently because they have time to adjust, consider and a moral obligation to select the best treatment decision for their child. The physician also maintains that parents facing an acute crisis confront a number of psychological elements such as denial and shock.¹¹² Hence, his narrative suggests that parental decision making abilities may be significantly affected by psychological factors, especially when making the 'right' decision. In medicine, the right decision is based on 'the best interests of the child' (i.e. as defined by the physician and the law), which, in the medical field and habitus, is formulated around sensible medical opinion. Medical opinions are based on assessment and surveillance of the patient and parents, which may lead the physician to conclude from a medical perspective that there is a parental failure to recognise of the seriousness of the situation. Another physician relates to this perspective and the parents' lack of psychological ability to accept reality:

So there was real confusion from them about what actually they wanted, you know stating very clearly that they wanted this child to have everything done but then, you know, getting very upset when the nurse comes in the check the oxygen levels - why are they waking the baby up? And I think there was a failure to recognise on their part how sick this child was, or failure to accept... And I think in fact that there was a lot of guilt in this as well ... (D4, pp.3-4).

'Reasonableness' in this instance stems from the notion that in a reasonable world, parents would normally accept that medical interventions are appropriate. Yet there is an element of 'misrecognition' (Bourdieu, 1984) in the above narrative because the physician seeks to legitimise actions that are based upon existing power relationships with parents who are subject to that power, and physicians who, by means of symbolic capital, express that power in ways that are perceived to be objectively 'normal.' In other words, the physician's world is one in which the order of things places medical authority as the norm, and parental resistance as abnormal. This physician also concludes that parental guilt leads to indecisiveness and resistance to the wishes of medical staff as they attempt to perform their normal duties (which are 'in the best interests of the child'). But why should a physician talk of parental 'guilt' in relation to decision making?¹¹³ He went on to imply that parents of seriously ill children feel immense guilt through worrying "about simple decision making" (D4, p. 17) and are therefore operating at a level that is far too subjective for sensible decision making. In the physician's own field and habitus, both simple and difficult decisions have to be made regularly. Thus, the

¹¹² These observations are similar to the parental anxiety, denial and even guilt noted in research concerning the experiences of parents in hospital care of the critically ill child (Carnevale, 2005; Carnevale, Canouï, Hubert, Farrell, Leclerc, Doussau et al. (2006).

¹¹³ In a Foucaultian sense, guilt has strong associations with 'confessions' and in western societies, confessions are associated with the scientific reformulation of discourses concerning morality and behaviour. Hence, 'guilt' suggests more than a moral opinion, it also suggests a conceptual 'stumbling block' to good (scientific, objective) decision making (Foucault, 1977).

physician's perspective differs from parents' perspective, as it is defined by reference to a medical field that prioritises the objective and rational over the subjective and emotional. Parents are perceived to be out of their depth, and they are therefore unable to appreciate the good sense and relatively guilt free rational decision making that medical representatives employ to do what was 'the best for the child'.

I mean with a lot of our families when we talk to them - these are difficult decisions to make for them anyway - we always talk about the position for the child and for the parent and they are unable to separate those out. They have huge amounts of feeling and concern for the child but then they also couldn't also separate out what was best for the child from what was best for them as well (D4, p.6).

The 'separating out' of what was best for the child and best for themselves reflects a type of binary thinking that may blur a decision making process considerably. In this narrative, a binary opposition is presented as an objective choice between what is best for the child and best for the family, whereas, in the parents' reality, both options are viewed within a subjective framework that is based upon "strong ties" that are quite different from the "weak ties" (Granovetter, 1973) that mark, in this instance, physician-parent relationships. As Murray (1996) points out, the parents' interest in what is best for their child is a mixture of self-interest and altruism based upon an intensity of emotional involvement that cannot be matched by any others, including medical professionals. This explanation of parental 'otherness' suggests a wide cultural divide from medical culture (Lupton, 1994a), and therefore begs the question – how do cultural differences contribute to parental resistance?

Cultural differences

There is evidence that physician-patient relationships vary considerably depending on the physician's attitude towards women (Lupton, 1994a), the elderly, the mentally ill, the unemployed (Wakeford & Allery, 1986) and a variety of other cultures and subcultures (Loustaunau & Sobo, 1997). Western medicine dominates the health care system in New Zealand, where most physicians are trained and work under a state healthcare system that is reflective of a modern, technological society that is similar to Great Britain, Canada, and Australia. Concepts of habitus and field (Bourdieu, 1984; 1992) may be directly applied to the social and cultural activities of medicine which are situated in a dominant matrix that is positivist and scientific. This way of being, as in 'the way we do things in our culture' (Latour, 1993) is taken for granted and is reasserted and in the process becomes visible in the moment that it is challenged or threatened by 'the other' (Foucault, 1977).

In the west, modern, scientific and medical knowledge may not necessarily be understood or supported by others of differing cultural backgrounds (Lupton, 1994a). Thus, knowledge, which is represented in this instance by the medical epidemiological field itself, exists in a particular material and geo-political context where surveillance and discipline becomes the norm. Subsequently in New Zealand, it is argued, non-Europeans are often treated differently from

middle class 'European' families, who generally understand the western notions of rational and reasoned debate employed by medical practitioners (National Advisory Committee on Health and Disability, 2002). Individuals and groups whose habitus and cultural mores do not overlap sufficiently with that of medicine become problems that need to be managed. This may be seen in the following example in which cultural differences are explained by means of reference to a Pacific Island 'colleague' who was once 'other' but is now clearly 'we':

It's very interesting too, different cultures having different ways of dealing with things. I've got a colleague who is from the Pacific and it's very interesting talking to him about information for families; and you know whereas for European families we much more try and explain why we're making the decision that we're making, and this is the rationale behind it. Whereas he was telling me, for a Pacific family, they don't want to hear that, they want to be told what to do. Just "tell me what to do". So it's a different message (D4, p 17-18.)

The above excerpt employs a form of linguistic 'othering' as European families normally elicit a 'we' response, whereas a Pacific Island family, a 'they' response. Doctors attempt to overcome the problem of cultural otherness and 'different ways of dealing with things' by concentrating on cultural issues as if they were just another objective hurdle to overcome. The ways in which cultural differences are addressed, however, imply that those of other cultures are not just seen to be different in their values and belief systems, but as in need of guidance and persuasion:

...I have to say that the availability of appropriate cultural input is probably not as good in our emergency department as we would like, but most often we can talk through these issues, and if it's something that definitely needs to be done, we can work our way through it. Very often all it takes is a talk from another doctor, like for example, if the consultant can come in and talk to the family and just...I always draw pictures, draw diagrams and I try and put things in very simple terms and talk about what might happen if we don't do [a medical procedure] (D2, pp. 3-4).

The physician talks about managing cultural differences in decision making through the employment of modified forms of communication, which is a rational and objective solution, but also one whereby cultural differences are reduced to merely ways of receiving and understanding information. But what of those parents whose values and beliefs do not fit easily with mainstream medicine and health care? In such circumstances, the 'otherness' is compounded, and the perceptions of causation becomes less flexible, more directly Eurocentric, and less tolerant. Such parents are then perceived to be simple, misguided or ignorant, and therefore much more liable to accusations of child neglect or even abuse.

Ignorance, arrogance, neglect or abuse

Bourdieusian arguments concerning habitus and cultural capital within differential relationships (such as expert/physician and non-expert/lay person) imply that those who are not cultural bearers of the training, wisdom and expertise of the professional should not challenge that expertise when it is offered (Bourdieu, 1984, 1988). To do so, is to put oneself in a position

where it could be argued that one was either speaking from a position of arrogance, ignorance or social ineptness.¹¹⁴ In the perception of parents as being unfamiliar with the physician's use of language and knowledge in a specific sense, there also exists the possibility of perceiving those from another culture (i.e. who do not share the basic language let alone an appreciation of medical knowledge) as being ignorant in a more general sense (Lawton, Ahmad, Hallowell, Hanna & Douglas, 2005). Yet this perception is incorrect, the key issue being the difference between the familiar and the foreign. The language of medicine is largely foreign to most lay people, and those from other cultures also encounter a foreign language within a context that is familiar to the mainstream culture, but not to them. Hence, as occurred in the Laufau case, physicians realise that the world of medicine was quite different from the parents' world by accepting the fact that this is exacerbated by language and cultural differences ("Specialist blasts system failures in cancer boy case", 2000). Hence, some parents are disadvantaged because of the problems associated with a language, environment and culture different to their own. These barriers to 'effective' responses from parents are exacerbated further if the parents are not of the same class, habitus or cultural capital (Bourdieu, 1984; see also previous discussion in Chapter Six).

Slippage between talk about parental resistance and parental abuse in the talk of the physicians interviewed suggest that the physicians place these practices in the same category as both groups of parents sometimes 'flee' the hospital. For instance, prior to the following extract, the physician was talking in general about parents who unexpectedly take flight from the hospital with their child, but then offered an imaginary incident based on past experiences of children being admitted from home with clear signs of bruising and/or broken bones:

...and we've got these concerns that the child's being abused, and so we'd like to do an X-ray of all his bones to see if he's got any other fractures, and we'd like to scan his head to see if he's got any subdural effusions etc' and they cotton on to what's going on, and partially – maybe they've got a guilty conscience - and they say 'to hell with this, we're getting out of here'. And then we have to know what to do. And what we do in practice is if we really think that things are not good, is that we will, if we have no choice, we will call the police and the police will go and fetch the child and bring him in (D2, p.22).

Child abuse is clearly immoral and illegal (and a different topic to the one being discussed in this thesis), but the same sort of stigma (i.e. as being abusers of their children) seems to be applied in this instance to parents who refuse medical treatment. The connection between resisting parents who 'flee the hospital' and child abuse is especially strong if the child

¹¹⁴ The argument that parents may be seen to represent a type of 'expert' in their own right (Chapter Six) is almost invisible within such discourses, be they from physicians themselves, the law (Chapter Five), or the media (Chapter Four).

subsequently dies. For instance, in separate excerpts reproduced from interviews with physicians, both freely referred to the Moorhead case¹¹⁵ as follows:

...I don't for a moment think that Mrs. Moorhead or her husband wanted their child to come to harm or to die particularly. But I think that they were extremely misguided clearly, and I think that in their case there's a peculiar sort of arrogance really -which is just my view – that they knew just on the basis of a rather quirky cult belief, they knew what was best for their baby and I think I feel that was a criminal level of arrogance and self deception really. And I think it's a very difficult area, but I think they were appropriately handled through the law. I personally think they deserved to go to jail for what they did and I think that is a very difficult thing, but that's a situation where this child clearly needed treatment and I don't think that would be very easy to argue against that view. And I would be strongly in favour of, if necessary, of being processed through...making them a ward of the court and then receiving treatment against the parents' wishes because their ideas seemed to be so way off and so clearly detrimental to the child in the opinion of almost anybody (D2, p.15).

The connection between parents as 'misguided' and arrogant is thus made, and when connected to 'criminal arrogance' and 'deserving to go to jail', an implication of child abuse, although not mentioned specifically, is very close. In the second excerpt, the gap between misguided behaviour and parental abuse is even narrower:

I don't see it any different from deliberately whacking your kid round the head, to be quite honest. I mean they knew they, they had the information, they could access that information, but they would not believe it and effectively killed their child. I mean, it's not that different, well, it is slightly different in terms they didn't purposefully harm, but at the same time they did. In society, from a kid's point of view, it was just the same as a smack round the head (D5, p.7).

The link between parents as being resistive to medical advice and abusive towards their children is thus clearly made in this interview extract, and, as in a number of previous examples, the issue of access and satisfactory parental responsiveness to supplied information is raised yet again.

Overall, the reasons offered by physicians for their difficulties with resistive parents ranged from behaviours that were perceived as expected, understandable and/or largely acceptable, such as psychological factors, to behaviours that were unexpected, malicious and largely unacceptable, often bordering on abuse. There are two main readings of this talk; firstly that the interviewed physicians are familiar with previous research and/or literature on the topic and therefore tend to refer to it during interviews; or secondly that there exists within medicine and medical research a particular way of perceiving the social world that is dedicated to seeking out causes of behaviour in others that reflects the surveillance-governmentality function of the medical gaze within both the medical habitus and the medical field.

¹¹⁵ As related in Chapter One, pages 9-10.

Discursive themes in physicians' responses to parental resistance

Modern medical training for practice engenders “a set of beliefs and a system of knowledge which structures the ways in which physicians diagnose illness and respond to patients” (Lupton, 1994a, p. 117). Preparation for practice is strongly underpinned by the positivist scientific method, which seeks to ‘discover universal truths’ through rational processes within a doctrine of (scientific) progress.¹¹⁶ In short, physicians are heavily influenced by a modernist imperative to define, categorise and ‘solve’ cases by examining every observable attribute, no matter how small. Hence, physicians not only actively seek to operate in the ‘scientific’ fashion, but insist that they be allowed to do so.

The result of is a form of discipline that is reflective of a “political anatomy of detail” (Foucault, 1977, p.139) whereby the person becomes the subject/object of an interplay of calculated ‘gazes’ intended to objectify patient behaviour and foster compliance and docility through normalizing responses and behaviours. As a result, in health care and medical institutions, the ‘body’ is enmeshed within a set of medically discursive practices that are themselves paralleled in other professions such as nursing or social work, or in other institutions such as psychiatric hospitals, penal and/or educational facilities ((Armstrong 1995; Foucault 1973, 1975, 1977; Peterson & Bunton, 1997); the basic overall aim being to control and organise, and most certainly to minimise resistance or forms of ‘otherness’ as defined through a set of scientifically established and commonly accepted norms and values in society. In situations involving parental resistance towards medical treatments therefore, it is these ‘norms and values’ that are challenged by the parents; in turn, it is these norms and values that are upheld by members of the medical profession through the means of the medical field, habitus and social capital.

Medical field, habitus, and social capital

Bourdieu’s (1984; 1988) works on class distinctions and disciplinary power argues that members of both academic and medical groups usually come from more socially elite class backgrounds.¹¹⁷ They therefore have a vested interest in preserving the status quo or of maintaining the ‘symbolic capital’ of their profession (Lupton, 1994a; 1997). In medicine, disciplinary prestige brings with it the notion of holding and maintaining knowledge (and therefore power itself) which descends through various levels of medicine from its professors,

¹¹⁶ Key features of this modernist, scientific approach involve rigid methods of analysis and categorisation, including the perceived need to examine facts and variables, isolate (out, usually) contextual influences, formulate hypotheses, and ‘generalisable’ solution to given problems.

¹¹⁷ Bourdieu’s characterisation of academia as a fundamentally conservative institution that reproduces and reinforces social class distinctions has a direct mirror in medicine (Lupton, 1997; 2003) and law (Kim, 2001). Subsequently, all attempts to challenge this conservatism in medicine, as in academia, are met with resistance from the vested power interests of the faculty to prevent ‘slippage’ of prestige and control.

consultants, surgeons, registrars, house officers, junior physicians and medical students. Furthermore, in ways very similar to academia, medical success continues to follow social origins and distinctions. Indeed, the process of delineating who within society may practice medicine, and how they may practice, is dependent on principles of division both at the macro and the micro levels.¹¹⁸ The divisions are therefore in effect an administrative function of the state (Bourdieu, 1984). Under such conditions, the state may be party to what Bourdieu (1977a) termed as 'symbolic violence', which implies control of the populace through subtle differentiations between those who are sanctioned by the state to hold certain powers, and those who are not.

Hence, the power of physicians is sanctioned through the power of the state; and power relations between physicians and the public come to be perceived by individuals as both necessary and reasonable, thus legitimising them in society. For Bourdieu, power is exercised in less visible ways (and is 'misrecognised' as such), being encapsulated in the order of things in what is thought to be 'normal' and 'appropriate' ways of maintaining social order. Bourdieu (1988) indicates the effect of symbolic capital through its operation via misrecognition is that the natural authority of both the state and its representatives is constructed as natural and legitimate.

The habitus of physicians in particular embody the assumptions, beliefs, and behaviours associated with the activity of 'doing medicine.' Such activities, which include the use of medical language and specialised equipment, the insistence on respect and special attention, the requirements of the ward round, the 'consultation', represent a particular type of socialisation that produces the types of medical credentials that serve to define and reinforce not only the professional-client relationship, but the contemporary social order as well (Bourdieu, 1986). Consequently, the social practices of physicians as medical agents are usually the result of various habitual schemas and dispositions (habitus), combined with various types of resources (capital) that they have accrued (Bourdieu, 1988, 1999; Fowler, 1997). These forms of capital are then activated by certain structured social conditions (within the medical field) to which physicians belong. Physicians therefore have a habitus that distinguishes them from other occupations, because they are the product of a medical field that is restricted to those with the right educational qualifications that rewards them with knowledge/cultural capital, status/symbolic capital, financial gains/economic capital, and power/social capital. To achieve

¹¹⁸ For instance, legislative divisions between state sanctioned practitioners and those who are not, differentiates between 'insiders' and 'outsiders', 'expert and layperson'. The divisions are therefore in effect an administrative function of the state (Bourdieu, 1984). In New Zealand, these differences are explicitly laid out in Acts of Parliament (such as the Health Practitioners Competence Assurance Act [HPCA], 2003).

and maintain these rewards, the medical profession has secured a legislative monopoly to practice and 'internalise' ways of maintaining their place in society.¹¹⁹

These forms of medical differentiation operate not only by maintaining social status and 'position', but also by reinforcing this difference as being a necessity born out of talent, effort and personal desire/ambition. The power within comes from the idea that the associated cultural capital of medicine is not necessarily 'handed down' as such, but 'built in' to the bearer of the credentials. This social privilege is therefore recognised not only by the client, but by the physician as well (Bourdieu, 1986). This in turn tends to produce situations whereby physicians expect to be believed and trusted automatically, and are both surprised and constrained in their responses to new and unexpected situations as, for instance, strong resistance to treatment proposals. In part, this response may be attributable to the presence of a medical *doxa*.

Bourdieu's (1982) use of *doxa* as a central dimension in the maintenance of a stable social field relates to characteristics that obscure the origins of the field, thus legitimising its knowledges and practices. This 'taken-for-granted' order of things includes a profession's perception of their most important functions and typical partners, as well as their impressions and definitions of their clients. In the medical field therefore, *doxa* relates to the beliefs inherent within medicine, such as the boundaries of medicine (and nursing), the types of people that are on a social par with members of the medical profession, the ways in which new physicians are prepared, and how health care practitioners should be perceived and treated. According to Bourdieu (1977a), it is the 'initiation rites', the training, skills and social relationships within and without the field, that tend to perpetuate a type of subconscious consent or "doxa-based submission" to its requirements among new recruits and professional members. The symbolism of all of this is unmistakable; a social field such as medicine contains all the constituents to produce not just a body of knowledge and skilfulness, but a set of differential power relationships within society. Such power is usually perceived to be exerted through the medical way of 'seeing' or 'framing' disease, illness and health care (Cheek, 2000), or as Foucault (1975) maintained, via 'the medical gaze'¹²⁰ within the physician-patient relationship.

¹¹⁹ As in, for instance, the use of the Medical Council, the Medical Association, Medical Societies, etc

¹²⁰ Foucault (1975) argued that because medical power was exerted through the development of 'the body' (as the object of the 'clinical' or 'observing' gaze which was defined, refined and developed through the 'contingent turns of history'), modern medicine became a science and an organised discipline that tended to separate the body from the person. It was therefore legitimated through a background metanarrative of scientific discourse which itself is now a part of the present discourse that underpins the notion that physicians can 'solve' nearly all human illnesses and therefore 'save' the body through the use of the medical gaze.

The physician-parent relationship

As implied by Lupton (1994a), Foucault (1975) and Bourdieu (1984, 1986), medical power and control depend upon the social acceptance of the long established status of the profession - which was achieved in part through the development and use of 'the medical gaze'- within the (socially sanctioned) medical field. The medical gaze refers to the notion that the physician may penetrate illusions and see through to the underlying reality because of:

...the suppression of every obstacle to the constitution of this new space: the hospitals, which alter the specific laws governing disease...the association of physicians, which prevents the formation of a centralized medical consciousness...and lastly, the Faculties, which recognise that which is true only in theoretical structures and turn knowledge into social privilege (Foucault, 1975, p.45).

In short, the medical gaze is maintained in modern society because it represents the new (i.e. scientific) discourse of medical-technological knowledge which itself is represented as a power base within society (i.e. as 'knowledge-power'). Subsequently, a physician can 'see' well enough to actually be able to diagnose problems, design treatments, and provide us with the benefits of his knowledge in numerous wise and learned ways. From the Age of Enlightenment, these ways have included examining the patient, asking them questions, and 'probing' for both the physical and the psychological being for clues as to the cause of the symptoms. Such a body of knowledge therefore came about from skilled observation within a relationship between the all knowing and seeing physician and the patient.

The physician-patient relationship is a process whereby physicians not only actively seek to operate in the 'scientific' fashion, but insist that they be allowed to do so. In this fashion, the 'subject' or patient becomes the recipient of an interplay between calculated gazes intended to objectify their behaviour - which is expected to result in compliance and docility - and normalised responses and behaviours at both individual and community levels. Such conformity, as Foucault (1977) observed, is a social and individual expectation operating at the 'micro-political' level in society. Yet, even though Foucault (1975) has shown how the physician-patient relationship may be deconstructed, and Bourdieu (1984) has critiqued some of the very dubious foundations upon which it rests, it is often described as if it were still operating under a functionalist perspective.¹²¹ Parents take their sick child to a physician, the physician applies an objective and scientific 'gaze', and all parties remain mindful of their ascribed roles and functions. It is therefore seen as uncooperative and outside the ascribed societal role for

¹²¹ The traditional view of the physician-patient relationship tends to rest upon the widespread popularity of the sociologically inspired 'functionalist theory' (Parsons, 1951, 1956, 1967). Parsons theorised that the concerns of individuals go beyond self-interest because it is in their own interests to conform to shared values and norms. Thus, for instance, parents look after their children, teachers teach them, and physicians treat their illnesses. Each individual has his or her 'place' and function, and the 'borders' between them are not meant to be transgressed.

anyone to rebel against the system and openly challenge or resist an individual who holds a position of power within the system. In fact, the 'rules' of the social interaction are quite prominent, and in the institution the patient plays a 'sick role' (which in the case of a minor may be intermingled with the parental role, i.e. seeking medical help, following directions, submitting to investigations, and so on); the parents play their assigned role (being there for their child, serving his/her needs, controlling behaviour, and comforting him/her when ill)¹²², and the physician plays the role of the 'legitimiser' of the illness (i.e. the director of medical inquiry, the provider of answers and a medical label, and eventually scientifically based treatment of various, socially accepted, kinds (Illich, 1977). This arrangement *demand*s a differential of power to succeed, the reasons being related to patient compliance and acceptance of professional expertise. Thus, it may be argued, the patterns of power evident in the relationship between physician and patient is a type of power that is socially constructed, maintained and promoted by widespread public acceptance (i.e. as a societal norm) of the illusion of control, both of the self and the state.

In cases of parental resistance to medical interventions, parents identified as difficult are isolated and singled out as a 'special case', one that goes against the norm; parental resistance is therefore (re)constructed by physicians, and also the law and media, as parental behaviour that is incorrect, wrong and unacceptable. For instance, in media related cases of parental resistance featured earlier (see Chapter Four), a common thread was the parental refusal to 'play' or 'dance' to the same tune as the physicians. This was especially so in the Moorhead case. In that instance, the medical need to control the parents became of paramount importance because they were taking a position that defied the (medically and socially) acceptable. They were uncooperative, they fled, and they were admonished because they resisted the established power networks. Such responses from parents are not perceived by physicians as 'the norm', and nor are they considered to be within the 'norms of society' (as discussed in previous chapters).

Doctors' responses to parental resistance

According to Lupton (1994a), "from the moment the patient walks into the waiting room or hospital, it is up to the medical staff to take control" (p. 118). The reasons why medical staff are expected to take control range from societal expectations of physicians (and to an extent, nurses) who are perceived to be 'experts' (Foucault, 1975) to the dominating nature of the field

¹²² As discussed in Chapter Six.

of medicine within society (Bourdieu, 1984).¹²³ The types of objectives (such as control and conformity) that physicians and allied health professionals pursue to govern the behaviours of others enables them to claim the high ground and maintain a privileged role within society (Foucault, 1982). Subsequently, it is not particularly difficult or unusual for physicians and their associates in health care to guide and control ‘non-experts’, i.e. patients, or the parents of child patients, who attend the institution seeking medical assistance. When difficulties do occur, established norms such as the pre-existence of trust in the medical expertise, the sharing of a common language, the acceptance of certain diagnostic and medical procedures, the need to accept the time restrictions of the institution, and the need, to a certain extent, to conform or ‘hand over control’ to medical representatives (Frank, 1999; Lupton, 1994a; Maseide, 1991).¹²⁴

As an example of the difficulties that physicians perceive that they face in the absence of some or all of the expected societal and medical norms, consider, for example, the following excerpt from one physician who chose to talk about the Moorhead case:

I mean there was just a huge area of issues of trust and mistrust with the medical profession historically from this family; they couldn't build up a trust relationship, and they couldn't even speak the language you know, in the sense of there was no common language to discuss their child's care. And there was a lot of, I guess, warning signs at the very first time that child presented to hospital; and the family were refusing certain radiological procedures, they were refusing blood tests, they were refusing, and yet they'd accepted at some level to have care for their child but they wanted it all to happen within a certain time frame. And they didn't want this, and they didn't want that, so they were being quite prescriptive about what happened to their baby and that was a control issue. I think they didn't want professional help, in my point of view they didn't want to somehow lose control and that somehow something that would happen to their child while he was in hospital and they were very suspicious that doctors would, I guess, whip them away and do something [to the child] (D3, pp. 8-9.)

This is a clear example of the use of the Bourdieusian notion of symbolic capital by a physician, who offers a summation of the requirements of parents within the medical field. A discourse analysis of the text reveals that there are those parental actions that are positively sanctioned and those that are not (see Figure 7, over page). In Figure 7, the practices that are intelligible within the medical field are juxtaposed against those that are not. This draws attention to the limits of both the medical and the parental fields, and also to the binary nature of the sanctioned/non-sanctioned cleavage that is imposed upon physician-parent relationships.

¹²³ In Bourdieusian terms, the relationship between physician and patient (or between the physician and the parents of the patient) could not only be described as paternalistic (with all the connotations of benign and altruistic intent that is sometimes inferred) but also as a type of social dependency. In this regard, Bourdieu's (1988), use of cultural and symbolic capital, with the main ideas relating to disciplinary prestige, orthodoxy/heterodoxy and faculty renewal, provides a very close correlation between not only the fields of academia and medicine, but also between medicine and law, both disciplines that, along with academia, possess social prestige.

¹²⁴ These ‘given norms’ are, of course, the given norms of medicine but only up to a certain point. For instance, there is considerable evidence that the language of medicine is far from normal within ordinary society (Welch, 2000).

<u>Positively sanctioned</u>	<u>Not sanctioned</u>
<ul style="list-style-type: none"> ● Trust ● the sharing of a common language ● the acceptance of common medical procedures ● the acceptance of a different level of care ● the diminishment of parental control ● the acceptance of professional help). 	<ul style="list-style-type: none"> ● Not trusting the physician ● the refusal to use a common language ● the rejection of common medical procedures ● the rejection of a different level of care ● the maintenance of parental control ● the non-acceptance of professional help.

Figure 7: Parental actions that are positively or negatively sanctioned by physicians.

The juxtapositioning of ‘good parent’ (i.e. medically acceptable) – ‘bad parent’ (i.e. medically unacceptable) behaviours continues in the physicians’ responses to parental resistance in the following sections of this chapter. In these responses, a variety of solutions to the problem of parental resistance were offered by the interviewed physicians that were aimed largely at preserving the relationship by improving communication, negotiating and compromising. The following sections represent an analytical account of the physicians’ responses to parental resistance.

Maintain the relationship

The nature of the physician-parent relationship was a constant theme running through all of the interviewed physicians’ texts. As previously discussed, this relationship is seen by physicians to largely depend upon the notion of all parties being mindful of their ascribed roles and functions, and each participant playing the correct part within their roles (Illich, 1977). Foucault (1982) maintains that power relationships themselves come into being through the exercise of power primarily through the use of language or discourses, as well as through systems of surveillance and by technological means, all of which are observable in any hospital or similar institution. For Foucault, discursive power relationships are never quite as clear cut or as definitive as they may seem. For instance, he postulated that power relations are contradictory and overlapping, incorporating a range of actors and institutions, i.e. “...there is in human relationships a whole range of power relations that may come into play among individuals, within families, in pedagogical relationships, political life etc...” (Foucault, 1984e, p. 434).

Within the physician-patient relationship, it is expected (by the physician at least) that parents will acquiesce to the authority of the physician on all medically related matters. In the face of resistance, physicians will firstly conclude that they have not made their position (and

therefore themselves) clear enough, or that they have not established a ‘proper relationship’ (whereby the parents will more readily comply with medical wishes). To do this, physicians consider it important to work on the relationship between themselves and the parents, and, as the interviews suggest, by making themselves and their position clear through improving the means of communication. In the physicians’ narratives, such work involves a range of strategies including improving communication, simplifying the language, negotiation and compromise:

Improve communication

The first step in the establishment of ‘proper’ relationships with resisting parents is seen by one interviewed physician as a simple improvement in communication, where sufficient time must be allocated to ensure ‘adequate’ communication. This generally matches the lay perspective, where the qualities of a ‘good’ physician are noted as including communication skills, trust and empathy (Lupton, 1996, 1997). However, in recent research performed in France (Carnevale et al., 2006) physicians’ communication skills with the parents of critically-ill children were identified as in need of considerable improvement. Nevertheless, as the following physician maintains, good communication with parents involves the establishment over time of a trusting relationship:

I guess there’s an element of trust involved in a medical relationship when you’re telling people that they need something. And I think most parents do trust with adequate time and adequate communication (D4, p. 14).

Trust is a central element in this narrative, and is recognised in most medical and related literature as being a vital requirement in physician-patient relationships (Brody & Engelhardt, 1987, Campbell, Charlesworth, Gillett, & Jones, 1997; Lasagna, 1962; Mechanic & Schlesinger, 1996). It is also a central feature in the narratives of parents (see previous chapter), and in literature relating to effective parent-physician or parent-nurse relationships (Bluebond-Langer, 1996; Grootenhuis & Last, 1997; Nielsen, 2004; Rushton & Glover, 1990). In all accounts, trust is represented as a two-way affair within the physician-parent relationship, and to achieve this, the physician is expected to balance scientific needs with humanistic ones; this is especially so if he is to gain the trust of parents, including resistive ones. This is possibly easier said than done, but as Wulff (1995) maintains, the patient-physician relationship may depend on the physician’s ability to put aside the more overtly biological and empirical components of decision making in favour of developing an understanding of the more subjectively focussed world of the parents.¹²⁵ There is also the possibility that some patients (or parents) may not

¹²⁵ See Chapter Three , pp.79-83

appreciate or welcome any physician led attempts to communicate on a personal level. That is, there may still remain the possibility that even within these refocused and 'subjectively orientated' relationships, there remains possible resistance to "an even more subtle operation of the 'clinical gaze' upon patients, reaching further and further unto their thoughts, feelings and everyday lives in unprecedented ways (Lupton, 1997, p. 492).

The relationship between physician and patient depends on effective communication, which in the following extract, is described by the physician as being developed by 'sitting down and talking to people':

I find that for something which has to be discussed - and I'm happy to do that - but it's difficult when you don't have a relationship with that family. You know meeting them for the first time maybe, and sitting there and talking about them, you know.....for the family (D4, p.18-19).

However, if the provision of adequate time, communication and trust does not seem to break down parental resistance, it may be that the use of language itself is the problem. Good communication between a health professional and a client starts with mutual clarity of meaning and understanding within discourse, even if that discourse is led by a physician (Camevale et al., 2006; Lupton, 1994a).

Change the language

The problems associated with overuse of medical language within medical encounters with the public have already been discussed in previous sections of this chapter, and play a part in the parents' narratives about communicating with clinical staff in the previous chapter.¹²⁶ The common idea that language needs to be adjusted by the physician to suit the intellectual or emotional level of the parents, in order for them to then 'see' the problem more clearly than before and accept the medical opinion is explained by the physician in the following extract:

I guess having met the family and met the child I should get some idea of what sort of intellectual and what sort of emotional level that they're on. You know I think sometimes too, we [paediatricians] like to sugar coat things a bit - I think we sometimes don't tell it like it is and I think we've got a responsibility. If we're asking parents to make a decision that has serious implications we have, our obligation to actually give them the appropriate information and give it clearly... I'm always very clear to patients that my job is to give them information and get accurate information of their choice, to make the decision, and ask any questions. I'm happy to help but I think that we have to give very clear information, and I think sometimes those simple words can actually be, yeah, are often unsaid (D4, pp.16-17).

It is not only medical language that is being adjusted in the above excerpt, but the decision making process as well. That is, it is argued that if the choices are very clear, the language simple yet factual, then even parents who are 'on a different intellectual level' should

¹²⁶ There is evidence that physicians are not very good at this adjustment, either leaving parents feeling that they have not received enough information (as occurred to most of the interviewed parents in Chapter Six), and/or not understanding what has been said regardless of being encouraged to ask questions or not (Hallström & Elander, 2005).

understand and accept the medical advice on offer. Once more, the physician supports the notion that access to information and understanding as a crucial part of making good choices; but there remains the possibility that some parents may still see things differently, even when they seem to fully understand what has been said to them. In such cases, improving communication and changing the language may not be enough.

Negotiate

The need for physicians to negotiate proposed medical treatments (or research) with 'consumers of health care' is generally perceived in present day western societies as being a 'given' that is not only reinforced by the notion of western individualism and the right to choose, but by legislation as well.¹²⁷ Regardless of any physicians who are lax at their responsibility in obtaining informed consent, negotiation is as much a legal necessity as it is a medical one. For those physicians facing parental resistance to their treatment suggestions, negotiation is perceived by some as vital, as the following interviewed physician maintained:

And that's, to me, that's the only way you proceed, that process of negotiation. You know if you - you know, there are very, very few families where you can't negotiate some sort of deal that helps both sidesand this to me gets the tick... But I know, I mean that's one of the issues is communication and negotiation. Communication across cultures is difficult, and communication across social class is difficult, and communication across physical distance is difficult, you know. There are lots of issues ...but very few situations where you can't establish some form of, yeah, you start negotiations. You can get someone (D5, pp.6-7.)

In this narrative, the physician's talk illustrates a form of medico-centrism (Loustaunau & Sobo, 1997) whereby medicine is implicitly identified with a particular culture and class from which it views the world and constructs 'the other'. Lupton (1994a; 1997) suggests negotiation between physicians and the recipients of medical care are not necessarily as straightforward as it may seem. In the above example, both cultural and class distinctions are offered as barriers to more effective negotiation between the holder of 'medical capital' and those who do not hold the same or comparable capital. Bourdieu (1984) observes that there are significant distinctions between social cultures and classes that may lead to misunderstandings and confrontations. In response to the problem of cultural difference, some physicians may 'bring in' another colleague who at least shares a part of the cultural characteristics of the resisting parents (see previous discussion on page 192, and also on pages 212-213); but for class distinctions, there appears to be less of a willingness to respect difference.

¹²⁷ As reinforced by the 'Nuremberg Code' (1949), the Declaration of Geneva (1948), the Declaration of Helsinki (1964), the Council for International Organizations of Medical Sciences (1993). See also the Code of Health and Disabilities Services Consumers Rights (1996).

Medicine as an institution is comprised of a range of interconnected and supportive elements held together by both the symbolic capital of medicine and the common habitus of physicians (Bourdieu, 1984). There is considerable power invested in not only each member of the collective, but in their combined efforts as well. In the following narratives, the physician talks about calling upon each others' services for help in convincing parents to accept medical treatment:

So my belief is that you should always do this in a peer supportive fashion and as far as possible in negotiation with the family. So I see the whole process as a negotiation rather than an imposition. What you do is, you know from my point of view, is start off with the family to debate the issue to feel what their feelings are about how to manage a severe illness - what their expectations are, what they see is in the best interests of the child. And then you also have an opinion, and you have peer support of your stance to make sure you're not out on a limb or have a particular sort of anti, you know, personal issue in it (D5, p.2).

In this extract, the opinion of the individual physician is associated with the personal, subjective and the emotional, but the power of the medical collective is used to promote the objective and the clinical. Yet if the use of peer support fails and the parents still refuse to budge, there becomes a point where some sort of compromise has to be attained:

...usually the process of negotiation goes at various speeds and you occasionally get to a point where you actually agree to disagree in that situation. And there's probably nothing you can do except face the situation at hand because my personal belief is if, whenever you're facing life threatening situations, the families have a free choice - whatever they've decided previously can go out the window. And they can state their choice, now whether the health services can actually support that decision? More than likely (D5, pp.2-3).

Here it may be seen that individualised notions of choice, and by implication, informed consent, are constructed as solutions to problems of communicating between physicians and families. Why parents may come to disagree in the first place is given little consideration in this narrative. 'Agreeing to disagree' suggests that when opinions are polarised, compromise is negotiated.

Attempt compromise

Compromise springs out of a collective medical desire to be regarded as less paternalistic and more 'partnership' orientated.¹²⁸ In such partnerships, which emerged in response to consumer demands for a 'user friendly' medical service that recognises the impact of market forces on health care (Lupton, 1994a; 1997), the need for a balanced relationship between physicians and their patients is reflected in a 'finding the middle ground' approach. For instance, an early attempt to find the middle ground may commence with reference to what 'normal' families might do:

¹²⁸ As already implied in the discussion concerning medical decision making in Chapter Three.

From a doctor's point of view it's facing a matter of raising the issue - and families usually raise that as an issue - saying, "this is what other families in this situation have chosen to do or have agreed to do" (D5, p.2).

This extract may be aimed at compromise, but the use of 'other families' and what they might agree to do in an attempt to offer a comparison that might help parents decide suggests the use of type of 'us' and 'them', 'normal/abnormal' 'good/bad' binary split that has previously been identified as a method of maintaining power through the use of normalising language. Alternatively, but still in pursuit of this idealised 'middle ground', and this time in a case where the physician thought that further medical treatment was futile, the following physician had this variation of the binary position to offer:

And often we have to wait; not so much time for the child but time for the family to let it all sink in ...So you go through that process and say, well this is what the two courses of action are: "you can carry on ...with very little prospect of recovery, versus withdrawing." ...but I think that course of action would bebut then it becomes paternalistic (D3, pp.5-6).

This physician resists the paternalistic approach suggesting that he would try to avoid using this strategy; the same physician later clarifies his approach to parents who use alternative therapies:

Compromise, I think, in my view is that parents will try all sorts of treatments particularly with children with either chronic illness or children with life threatening illness; meaning most parents will try some form of alternative therapy. And I want to be as open as I can about that so at least they feel they can tell me what treatments the child was on and I in turn try not to be critical of them for doing that because I can understand why the parents would want to do anything they can for the child. So my role would be to see how we could accept alternatives that could be used in addition to orthodox treatment. ... [It] wasn't a standoff situation which sometimes arises where they're told by alternative health practitioners to stop using conventional therapy; that it's not going to work and they should be using alternative therapy. I would prefer to take the view that as long as they don't interfere with each other that they continue both (D3, p.9).¹²⁹

Compromise is attempted, the reasons for parents seeking alternative therapies are accepted, but the treatments may still be disputed by physicians. This physician suggests that 'we' (the combined collective of modern medical practitioners) accept any alternative treatments alongside 'orthodox' treatment, but a line may be drawn when alternative treatments affect conventional treatment regimes. Yet compromise, or any other form of negotiation with the resisting parents for that matter, cannot be entirely effective, when parents remain disadvantaged during the delivery of information that is based on the privileging of medicine as 'orthodox' treatment, and other alternatives as 'not orthodox', i.e. not sanctioned by medicine.

The transition from beginning relationships to improved relationships and communication, to giving parents more time to think, to attempts to modify the use of language, to negotiating and attempting compromise is not necessarily an easy one. One of the main problems being the persisting notion that physicians should be able to make a more reasoned and objective decision

¹²⁹ There are distinct similarities in this narrative to the (media reported) material offered by the physician in the Liam Williams-Holloway case (see, for instance, pp. 100-102, Chapter Four).

than parents, that their knowledge base is the superior (orthodox) one upon which all decisions ultimately rest, and that this path is the right path to go down. These notions are akin to medical paternalism.¹³⁰

Revert to paternalism

Within the practice of medicine there remains a relatively high degree of paternalistic behaviour, regardless of more modern moves to share the decision making process as an attempt to balance power between physicians and their clients. The notion of paternalism depends mainly on the idea that some people are deemed unable to, or are otherwise incapacitated from, making rational choices for themselves. Traditionally, it is 'the very young' or 'the mentally ill' who are seen in such a light, but in various ways, so too may anyone else be perceived to be in need of guidance, according to situation and their responses at the time. Therefore, when acting paternalistically, physicians face a tension between the need to respect that person's autonomy and their perceived professional and societal obligation to help others. Foucault's analysis of the operation of power suggests that physicians would be more likely to resort to paternalism when the course of treatment is clear and the outcomes certain. Marshall (1990), commenting on Foucault, suggests that, for example: "The degree of rationalisation in the bringing into play of power relations in a field of possibility may be more or less elaborate in relation to the effectiveness of the instruments and the certainty of the results"(p. 24).

Physicians justify acting paternalistically toward parents if, and when, they consider the autonomous actions of parents to be unacceptable to the norms and/or perceptions of medicine. To achieve this, they will usually maintain that the actions of the parents will lead to harm for the child (or a greater harm than the proposed treatment) and that they are therefore acting in the child's 'best interests.' This argument involves both the use of a very effective conceptual instrument combined with the scientific certainty of results, and is therefore a powerful control mechanism under such circumstances. Once more, in the following variations, the use of language as a means of effective communication is perceived to be an important means of persuasion. In the interviews with physicians, there were numerous examples of the subtleties employed by physicians in what remains arguably a variation on paternalistic behaviour. The following represent the main variants of paternalism that emerged from these interviews:

Reattempt all previous negotiations/compromises

In situations where continuous attempts to renegotiate difficult (ethical) situations have stalled, compromise has been recognised as a way to enable reasoned decisions that "respect the

¹³⁰ See previous discussion in Chapter Three, pp. 79-80.

conflicting values of all parties” (Fry, 1989, p.152). However, as nurses have maintained in disputes with physicians, even this approach brings ‘compromise’ at a price, because it is often tempered by an insidious amount of medical paternalism (Grunstein-Amado, 1992) which is a form of institutionalised discipline (Foucault, 1977) achieved through the use of symbolic capital and, often furtively, through symbolic violence (Bourdieu, 1977a, 1991). Paternalism may be used in cases where parents appear to be resisting the directions of physicians, although initially, this strategy may be quietly put aside in favour of a considered and balanced approach in the hope that it may yield potentially satisfactory results:

...I think one of the things that helped literally was that one of our more experienced doctors on the ward sat down with the family one day and specifically asked them what they understood was the problem to try and get a really good idea of whether they really truly did understand the problems that this baby faced. And it was something I hadn’t done, but I realized that they were fairly bright people ...and it actually came back that they did actually understand what was wrong with this child... (D4, p.2).

In this narrative, lack of cooperation is associated with lack of understanding about the baby’s health problems and therefore the appropriate parental response to the situation. Once again, the problem is seen as a failure to ‘sit down with the family’, to make enough time to communicate effectively with the parents so that they will make the ‘right’ decision. The physician maintains that the right decision requires the parents to be ‘sat down with’ (an appeal to subjectivity/emotionalism) and given a reliable and objectively devised medical recommendation. In other words, they are expected to understand and accept that they are being medically guided in a ‘slightly paternalistic’ fashion.

Another physician suggests that parents usually expect a degree of medical paternalism:

And once you’ve got the explanation and you think that its been received by the families and you’ve answered their questions as best you can - for most families, they will adopt a position of ‘what do you think is best’ because they find it, and I think for probably, you know, the majority of situations, that position becomes slightly paternalistic... (D3, p.5).

This physician regards medical paternalism as a norm, and implied later that parental choice in medical matters was a distraction rather than a help. The physician argued that he would communicate with resisting parents in a fashion that not only offers possibilities but steer them towards the best (medical) one:

“I recommend the following piece of action” rather than “what do you think we should do?” I think that’s too hard for families, and so what you try and do is set out the likely scenarios on what might happen, which is this path or course of action as opposed to that (D3, pp 5-6).

Some parents continue to resist medical advice, and as the following excerpt shows, an alternative angle is then attempted that combines compromise, persuasion and paternalism:

There are occasions when we know that families present as “prickly families” and we know that some of the questions they ask indicate that it’s wise to consider with those families all the wider alternative options right from the very beginning and accept and encourage families to express what would be their terms for engagement with the system. And then to say “well yes of course it’s fine if you do so and so” and “yes we’ll take that into account” and “yes we’d like to integrate that into our treatment plan. Will this make it easier for you to accept the conventional medical advice we’re offering you from the literature?” And so yes I do think we go out of our way in some cases to ensure we that we don’t reach a confrontational situation which will force the family to make a

decision which avoids, “yes, we’re going to bow completely to your medical orders” or “no, we’re not going to have anything to do with you” (D1, p. 3).

The above excerpt brings into focus not only the ways in which physicians may problematise a situation that involves parental resistance, but also the way in which a physician may seek a way around that problem by attempting to maintain some degree of parental autonomy. The careful use of the phrases ‘conventional medical advice’ that is supported by ‘the literature’ still suggests the superiority of medical literature, and therefore medical opinion, over other alternatives. In this regard, it is as if the physician is attempting to steer the progress of medical treatment alongside alternative treatments, but only as long as such treatments are ‘harmless’.

Permit harmless alternative treatments/therapies

Alternative treatments tend to be appraised by physicians as belonging to two distinct camps, that is, as relatively harmless or dangerous and suspicious (Ernst, Resch & White, 1995); yet overall, most New Zealand physicians know very little about ‘alternative medicine’ (Ernst, 2006). In a sense, the gradual acceptance of some forms of alternative treatments in medicine has allowed medicine to maintain a more ‘modern’ public position, as if it was really intent on becoming a more open-minded and less ‘patch protective’ profession (Owen, Lewith & Stephens, 2001). In pursuit of this more ‘open’ position, many New Zealand physicians have recognised the value of patients from ‘different cultures’ (i.e. different to the dominant pakeha culture¹³¹) using their own health care providers and traditional treatments. For the more increasingly inquisitive members of the wider public who wish to experiment with different modes of treatment (Lupton, 1994a), medicine has also seen the value in ‘moving with the times’ and has ‘admitted’ into the broader circle of medically affiliated professions a number of alternative therapies (such as acupuncture, hypnotherapy, and chiropractics).

Subsequently, there has been a significant degree of ‘relabelling’ of alternative therapies in recent years as ‘complementary and alternative medicine’ (CAM). This suggests not only a softening of the orthodox position on alternative treatment approaches, but a gradual and sometimes rather grudging acceptance of change.¹³² Nevertheless, in this new position, there remains a Foucaultian element of maintaining a power base through discourses of judgement and control: As one physician maintained:

... my philosophy is that whatever people want to do to try and help their child is fine by me as long as it doesn’t cause any harm to the child so whether that’s having people praying for a child or, you know, doing gentle massage or anything ...and its interesting sort of from my years of starting in child health we just didn’t hear about it but now I hear about it a lot (D4, p.3).

¹³¹ ‘Pakeha’ is a Maori term that is in common usage in New Zealand; it signifies non-Maori white persons.

¹³² See discussion on page 108, Chapter Four.

Judgement and control is articulated in this extract by references to the avoidance of ‘harm’ which is defined by the physician as being anything that goes beyond low intervention responses such as praying or ‘gentle massage.’ Such a position is therefore clearly defined by what is acceptable to the physician rather than the parents:

I guess the difficulty comes when that challenges what you’re trying to do. You know I think it’s, I mean my philosophy is sort of [based on] mutual respect in that you know if somebody else is doing something then they need to respect what you’re doing as well. And as I said, as long as its not, you know, I’m a bit cautious about them giving babies tablets, or pills or potions or whatever, but you know for simple, simple measures in particular, you know, praying and things, then there’s no problem at all (D4, p3).

For this physician, ‘praying and things’ is sanctioned, but interfering with the physician’s work, or giving ‘tablets, pills and potions’ based on alternative treatments is not.¹³³ On occasion, the problem for the physician is not so much the parents desire to use alternative treatments, but a refusal to use recommended orthodox medical treatments instead. For instance, the same physician went on to argue the following:

It’s not something that’s uncommon, I guess, not to the extent of being a life or death situation sometimes. I think of a child that I look after whose got significant brain damage and has fairly regular seizures and the mother chooses then not to have this child on anti-convulsives. And very clearly, my feeling is and I’ve explained to her very clearly that I feel, “look, this could be actually impeding the learning and also that there’s an increased risk that she could die” ...because she’s not on treatment. And this mother is intelligent, English as a first language, she understands exactly what is being said to her ...and she still chooses not to use anti-convulsives and that is because of her fairly fixed beliefs about that (D4, p.14).

The physician struggles to understand how a mother who is intelligent, articulate and understanding of the situation could come to an alternative conclusion about the recommended course of treatment, i.e. that she does not share his/her world view. By implication, the physician constructs parents who are unintelligent, have English as a second language, and do not understand the seriousness of the situation as those who are more likely to resist or refuse treatment for their child.

Redefine the meaning of ‘normal’ treatments

In the case of medical practitioners being more in tune with the traditional healing practices of other cultures, and in light of changes in medical perspectives towards alternative approaches, attempts have been made by physicians to ‘redefine’ the meaning of normal treatments to be more inclusive of other possible treatments that are tolerated within both the medical field and the wider community. As the following physician suggested:

This often happens for example in the Pacific Island community, they will access traditional Island medicine in the form of massage or potions and tonics and things that are rubbed onto the skin. Many of these don’t compromise the child’s care - sometimes they do. But most alternative

¹³³ N.B. A more extensive list of possible CAM therapies is available in Appendix 7.

medicines, and the evidence for them is pretty slim, but most of them are benign. There are some exceptions where alternative medicines are actually toxic, and there are good examples of that, but that's the minority (D3, p.10).

This narrative implies that, the 'toxic minority' aside, the increasing use of alternative medicines appears to be acceptable to some physicians, and that they embrace them as being of some (if limited) therapeutic value:

And for most of them in my view, there are those that work. But I would still - because they're important to the families' health beliefs - I would prefer to carry them on, because often we work with the family. If you're not undermining their health beliefs, as long as it doesn't compromise the orthodox medicine, which is more likely to cure than alternative medicine (D3, p 10).

Within this physician's use of certain discursive phrases, there remains a subtle resistance to alternative medicine, and a suggestion that there is a hierarchy of medical knowledge that places traditional alternatives nearer the bottom (which is 'unorthodox' and therefore less likely to cure), and modern medicine (which is 'orthodox' and 'more likely to cure') at the top. This unease over the use of alternative medicines does appear to fade if the emphasis shifts from 'cure' to 'comfort'. For instance, at this point, it seems that alternative may even become 'normal':

And I think it's really opened my eyes to having a wider range of what we would say would be normal treatment in that you know. As I said, you know, I think the bottom line is keeping the child comfortable and making sure that they're not suffering, but I think that's the bottom line and I think you know the other things are negotiable in terms of, you know, for a child who is palliative, he's clearly got a life limiting condition and quality of life is severely affected (D4, pp.9-10).

It is therefore another matter when medicine cannot cure an ailing child, or, as in the following excerpt, when the child has no particular chance of ever responding to conventional medical, or alternative therapeutic approaches:

The child is having alternative sort of therapy for her cerebral palsy as well. I guess that, for some things, you have to put that to one side to maintain a professional relationship with that child or with that family (D4, p.14).

Maintaining a professional relationship remains important for the physician, and thus even 'harmless' or marginally unconventional alternative therapies may be tolerated within limits when a child is seriously ill but may yet respond to medical treatment; but when a child has a life threatening condition all normalising talk involving medical tolerance to alternative treatments begins to waiver:

... but I guess its different if its a life threatening condition, I think there's just no sure - I think the child has to come first. You know, I mean my feeling is, I'm fine for a family to have a particular belief as long as it's a decision that's going to affect them not you know, not the child (D4, p.14).

In this instance, the line is more clearly drawn, and the paternalistic edge of the physician-parent relationship returns. In such situations, physicians may seek to reinforce their positions with parents by seeking support from others associated with healthcare delivery.

Seek support within the institution

There are a number of ways that physicians seek further support in maintaining their position regarding their choice of treatment of a seriously ill child in the face of parental resistance. In the medical interviews gathered for this thesis, one of the most common methods was to seek secondary support. In the medical field, this often involves either seeking a second opinion or making use of ‘ancillary medical staff.’ Traditionally, the ‘second opinion’ has been used by both patients and physicians alike when both are faced by a medical quandary that is not resolvable in the first instance.¹³⁴ At times, seeking a second opinion has been seen as a negative response undertaken by a disgruntled patient who has not been satisfied by the treatment offered by a physician (Lupton, 1997). However, in the following extract from a guide for parents negotiating with the medical profession, a second opinion is represented as routine and necessary condition for informed decision making:

A second opinion is nothing more than obtaining another viewpoint. A second opinion is not only related to medicine but all walks of life. The opportunity to gain multiple views and perspectives can help anyone make a more informed decision. In the medical world, a second opinion occurs when a patient or a child's parent requests a second physician to comment on the condition of their child. The second physician will discuss with you your child's diagnosis, treatment plan, and pertinent information. ...The acquisition of a second opinion does in no way and should in no way threaten your physician or his professionalism. A second opinion can, in fact, help to solidify the bond between you, your child and your physician (Pappas, 2006).

The second opinion is also used in medicine as a way of consolidating support for a particular course of action:

Well you would usually give it a bit more time, and you would maybe get a second opinion...I mean normally in those life situations there would be, you know, several people involved. It's never made nice relations - several doctors might be involved in that decision. If we're all agreed and the family just need more time, then that would quite commonly occur where the child might remain in intensive care for a week to 2 weeks to 3 weeks and then for a further discussion to be made (D3, p.6).

The physician suggests that medical staff make complex decisions collectively by all working together towards a common goal. It is evidence of the presence of a shared medical field and habitus draws upon the strength of the collective and uses consensus in order to impose a particular viewpoint (Bourdieu, 1991). Within the medical field, a second opinion is sometimes employed covertly and without the parent's knowledge. The second opinion recognises and pays homage to the medical habitus which is a self supporting mechanism (Lupton, 1994a) that draws upon the cultural capital of peers who embody the institutional power (Bourdieu, 1991) of medicine. As another physician stated: *“Whenever I talk to a family...I have regard to colleagues, and of a senior colleague or a peer's opinion that I'm, you know, doing the right*

¹³⁴ As an example, see p. 178, Chapter Six (Rose's story).

thing" (D5, p.2). This strategy of drawing upon the strength and power of the medical collective may also be employed strategically by other members of the clinical staff who seek out supportive medical opinions in an attempt to reinforce the original advice:

The staff in the unit found this family challenging, and also felt that the family didn't believe what was being said. And so their way of trying to counteract that was to have a different consultant talk with the family every time, um so that they weren't getting one view so they could see it wasn't just one person's view that this baby was going to have lots of problems. However the down side to that is I think that they didn't actually develop a relationship with anybody to trust because they saw multiple people. I know that that was a deliberate strategy and I think that in retrospect that probably wasn't the right strategy (D4 p.7).

The physician comments that in this situation a lack of continuity of care may be an issue. He also implies that it is usual for one physician to be in charge of a particular 'case.'

An alternative or adjunct to the use of other physicians is to employ the assistance of other actors within the health care field who provide an ancillary and/or supportive role:¹³⁵

I make a lot more effort now to, like certainly from when I first started working, to involve interpreters, and also to involve cultural support workers and culturally appropriate nursing staff or allied staff ...to work with me (D4, p.14-15).

The use of allied staff thereby increases the number and frequency of institutional contact with parents. As allied members of staff, such as nurses, are subservient to the consultant, the overall effect is to convince resisting parents that they should accept the medical position. Nevertheless, there remains some cases where the parents still waiver or seek a second opinion and/or other forms of treatment (i.e. from non-medical sources, such as from a CAM therapist) for their child, and the physician is placed in a difficult position. In such circumstances, the physician may seek support from a source outside of medicine, but viewed as an ally of medicine.

Appeals to a stronger form of paternalism is consolidated by ideas about the position in society that is held by physicians as the arbiters of 'good/bad' medicine, the commentators on human rights in society, the scientific authorities on the value of orthodox medicine, and even the 'callers of the odds' of treatment:

I think in this country we don't value children's lives as highly as we should and I think we value family rights above children's rights which I think is wrong in that somebody needs to take a step back and say what's actually best for this child - you know if this child has got a 50% chance of living - I mean surely that is something you can't ignore. And I guess it's looking about longer term, you know, what's their quality of life going to be as well but, I mean gosh for my mind that's just clearly this child needs to go through that (D4, p.12).

It is at this point that the more benign forms of medical paternalism may give way to more dominant varieties, and, as the physician now makes very clear:

And the [resisting] parents have to, I mean if the parents are not prepared to do that; I think there has to be a proviso, there has to be adequate communication but even if that's been gone through, and maybe somebody impartial involved in making sure that the communication had been given,

¹³⁵ This aspect of medical paternalism is more fully developed in the next chapter of this thesis.

and yeah all cultural language issues are taken into account, then I think its appropriate for the law to get involved (D4, p.12).

Physicians who encounter the problem of parents who spurn conventional treatments may employ a range of strategies to ensure treatment that they consider to be 'in the best interests of the child' including seeking secondary support, redefining the meaning of 'normal' treatments, and negotiating and renegotiating until some sort of compromise is reached. However, some parents will not change their minds regardless of all of these strategies. In such cases, physicians seek out ways to strengthen their position even further.

Use the law as an ally

What happens when after all the medical attempts to communicate more effectively, to establish a better relationship, to benignly steer, control and even compromise with resisting parents fail? When parents continue to resist all of the previous subtle means of exerting more power and control, the relationship between knowledge and power in the discourses of the human sciences (such as psychiatry, medicine, law and others) and the practices of governance (through the use of legal discipline) come into effect. Governmentality is characterised by surveillance and discipline which is applied to the masses through "a whole series of power networks that invest in the body, sexuality, the family, kinship, knowledge, technology and so forth" (Foucault, 1980d, p. 122). The 'power of the state' is maximised through the state's regulatory mechanisms which include medicine, psychiatry, education, social work and public health by legal means. All representatives of such disciplines may therefore make use of various laws such as the Children, Young Persons and their Families Act, 1989 or the Care of Children Act, 1994 if they deem it necessary. As an extension of the role of the state as the 'guardian' of individual rights within institutionalised historical settlements, physicians and others are able to act in certain ways according to perceived need. Law and medicine are strongly related through their interconnectivity to forms of institutionalisation which itself combines traditional predispositions, legal structures, and practices relating to custom or to fashion (Foucault, 1982).

As previously maintained, the use of the law to enforce a desired medical treatment is a development that is resisted if at all possible by many physicians, and ways are found to avoid such a manoeuvre whenever possible:

If the family continued to refuse, and there's not many situations where I've been involved where its gone that far, ... you could (and I've never done this), but you could take it to a legal [level] or appoint an advocate for the child and in the sense give the court authority to back up your, I mean, the child. I think there are precedents where that has happened...but I've never been involved in that. So normally by the process of explanation and support we get through that (D3, pp.6-7).

This physician suggests that in circumstances where attempts to persuade parents to accept medical treatment through the usual process of explanation and support fails, as does references to the law and/or by working in ways that are within the strict boundaries of appropriate legal

statutes or regulations, then legal means, often through adversarial court actions, are required - as the same physician goes on to explain:

...there was a child that required a blood transfusion ...the child was anaemic, and as a result of prematurity and that would be quite normal practice to transfuse premature neonates to keep the haemoglobin up until such times they make their own. And wetold the parents that the child needed a transfusion and they said “we don’t” because of religious beliefs. And there was a stand-off, and what happened was that they left the unit for a day and while they were away we transfused the baby which we were able to do under various pieces of legislation ... the Guardianship Act, etc. (D3, p.7)...The family essentially turned a blind eye - and other people have described this, where they put up resistance but in the end of the day they couldn’t oppose it because there were two pieces of legislation that allow us to give blood transfusions for life ...and so in a way that was a face saving move from their point of view - they left the ward. While they were away the child was transfused, they came back and nothing more was spoken about it. But I’ve never had this situation where we’ve had to force treatments through the court but there are many examples in New Zealand where that’s happened (D3, pp.7-8).

The physician suggests that it is sometimes highly likely that legislation will be used by members of the medical profession as a way to force parents to accept medical treatment for their children. In this excerpt, treatment is carried out in the context of parental absence and medical silence and legislation provides the framework for treatment to occur. Pre-existing legislation and a standardised process for gaining legal consent through the courts are routinely deployed in cases where the treatment is considered to be effective and the results certain (Marshall, 1990). This extract illustrates the way that consent, which is usually constructed as an individualised concept negotiated between physician and client, is also a collective property protected in legislation and enforced by medical and legal actors (Austrin & Phibbs, 1996). In order to maintain the integrity of their religious identities as Jehovah Witnesses, the parents are forced to exit the hospital and to maintain silence about the treatment. The above interviewee also differentiates between the routine use of legal means and going through the adversarial court system in order to ‘force treatment’.

The power of the law has been more fully discussed in Chapter Five, as is ‘going through the courts’, but if physicians perceive that such actions are rare – because they avoid such situations whenever possible¹³⁶ - then under what circumstances is ‘the full force of the law’ used on parents to settle decision making disputes? One physician put it this way, physicians will use the law when a child’s life is at risk, *and/or* the parents show no remorse about the death of their child caused by resistance to medical treatment:

[Talking about the Moorhead case] No, I think it’s appropriate - I followed the court case. The parents seemed to have no remorse about it and therefore the next child’s at high risk. I would have to compare that 5 years sentence. I don’t know what 5 years represents, what that’s equivalent to. Is that the same as someone with drunk driving or you know, I’ve got no way of

¹³⁶ For instance, it is a common belief that physicians involved in the Laufau case avoided legal action until *after* the child was dead.

kind of comparing it. Five years in prison for... I suspect would be a good example where it's inconsistent across the legal system that it probably there'll be other people who are, have been in prison for much less... (D3, p. 11.)

In this, the final extract, the powerful connections between medicine, the law and regulation and control of behaviour that is exerted by state sanctioned mechanisms is illuminated. As this interviewee suggests, physicians do follow such cases with considerable interest, and they have opinions about such cases that often support the law. The conclusion is that the law is an ally of medicine in these matters, and any parent who has rejected all of the means provided by physicians to alleviate and rectify the awkward impasse that is caused by their resistance may eventually be subjected to the due processes of the law should the physician deem it necessary.

Summary

This chapter has presented an analysis of parental resistance from the perspective of the physicians interviewed for this thesis. Within the parent-physician relationship, it has been shown that there are several discursive elements that directly relate to the physician's viewpoint which is embedded in sets of ideas about the role of medicine, as a particular culture, within society (Lupton, 1994a). The physicians interviewed for this project identified the causes of parental resistance that were similar to health, medical or biomedical literature. These causes include religious or philosophically different belief systems (that are not 'mainstream'), psychological factors, cultural differences, and ignorance, neglect or abuse. That these perceptions are to be found in medical and associated literature is confirmation of the position of medicine as a dominant discourse. The interviewed physicians' understandings about and responses to parental resistance differed considerably from the parents ideas and responses which were based on their realities and experiences of the parent-physician encounter (as discussed in Chapter Six).

For the interviewed physicians, parental resistance is a problem that should be addressed through better communication, the use of different language, negotiation and compromise (but only of a limited variety). If these methods fail, a physician may revert to paternalism and push on with fresh attempts to renegotiate the situation, even deciding to 'allow' alternative therapies, but only in as much as they do not interfere with the traditional and 'scientifically sound' medical treatment. Other methods of responding to parental resistance include the use of other physicians to support the physician's position, and attempts to redefine the meaning of 'normal treatment', i.e. to change the usual meaning of language to suit a given (medical) position. If all else fails, physicians suggest that they are willing to utilise the law. Such acts are therefore quite clearly connected to Bourdieu's (1991) argument (that introduces this chapter) concerning the use of legitimate symbolic violence. Parents are exposed to several 'symbolic strategies' that impose the medical agents' vision of the divisions of the social world, and physicians are quite capable of any official naming and symbolic imposition of the medical discourse if and when necessary. As delegated agents of the state, and therefore the users of the strength of the medical and legal collective, physicians do indeed hold a monopoly on legitimate symbolic violence.

CHAPTER EIGHT

Being 'in-between': Exploring nurses' talk about parental resistance

Being a moral agent and enacting moral agency involved working within a shifting moral context; working in-between their own identities and values and those of the organizations in which they worked; working in-between their own values and the values of others; and working in-between competing values and interests (Varcoe, Doane, Pauly, Rodney, Storch, Mahoney et al., 2004, p.319).

Introduction

In this chapter, the narratives of five nurses form the basis for discussion. The chapter seeks to draw out their understandings of parental resistance, the discursive themes that influence their explanations and responses, and their perceptions of their role in responding to it. As in previous chapters, the discussion is underpinned by selected ideas from Foucault and Bourdieu, and more closely supported by the introduction of a third source of analytical material from Bishop and Scudder (1985, 1990, 1991, 1996) and Varcoe et al.(2004). The chapter proceeds by examining nursing views on the reasons for parental resistance before discussing the theoretical themes that provides a backdrop for an analysis of the nurses' narratives. This framing centres on the 'in-betweenness' of nursing, as an occupation that is caught between 'old professionalism and new professionalism'. This is followed by the nurses' perceptions of their roles and responses to parental resistance in practice, which are significantly different from those responses of physicians, and include main discursive elements such as the nurse as a medical collaborator, a 'team player', and an expert 'go-between.'

Bishop and Scudder (1985, 1990, 1991, 1996) note in their examination of nursing as a caring profession that nurses are frequently caught in an "in-between" situation. This situation involves the maintenance of multiple relationships and obligations between themselves and physicians, patients and their relatives, and hospital administration. Accordingly, even though a nurse's primary concern is the welfare of her patient, she may have to deal with others (such as parents, or physicians, or hospital administrators) who seek to influence her patient's welfare in ways that may be different from her own. Such 'in-betweenness' is often viewed as an invidious position where a nurse may find herself 'caught' between the needs of differing parties, or beholding to the requirements of multiple parties, with subsequent mixed loyalties and role confusion.

Analysis of the nurses' interviews suggest that that, as actors in their own and also in some parents' and doctors' narratives previously considered, nurses have a more direct influence on parental resistance than is indicated in the literature on child-parent-nurse relationships in a hospital setting (Darbyshire, 1992; Nielsen, 2004). This is because in most related literature, nurses are often claimed to be involved in activities such as 'guiding and supporting' parents

(Broome, Knafl, Pridham & Feetham, 1998; Hockenberry, 2004; Potts, 2002) but not necessarily being heavily involved in radical cases of resistance between medical staff and parents. This may be a reflection of their activities as primary professional carers for seriously ill children, and as key liaison personnel between themselves, doctors and parents. In these roles, nurses occupy a position that is 'in-between' (Bishop & Scudder, 1990, 1991, 1996; Varcoe et al. 2004) parents, doctors and institutional representatives (such as managers). However, being 'in-between' also means that nurses do not consider themselves to share anything like the same social capital as physicians (who are not 'in-between' in the same fashion as nurses) within the health care field; this difference is reflected in the ways that nurses respond to parental resistance.

It is argued in this chapter that it is this very 'in-betweenness' of nursing that is a resource by which nurses may understand and support parents who are often themselves in a liminal (Turner, 1979) or in an in-between space. Yet, it is also recognised that the liminality of nurses can be a double edged sword, whereby they are able to reflect on, and intervene within the relationships between doctors and the parents of a seriously ill child, but also find themselves held back from intensive therapeutic involvement. Thus, it is maintained that nursing discourses on parental resistance depend heavily on nurses' perceptions of their identity, role and place within 'the system', which is, in turn, strongly related to recent developments in what may be termed the 'professionalism' debate. Whilst there is very little directly said and implied by the nurse interviewees about the impact of their skills as nurses (which was a major factor for parents in their responses), it remains evident that they occupy a place within the care of seriously ill children that is a crucial one. Their relationships with the parents of child patients are complex and contradictory, being primary to care yet secondary to medicine, profoundly important to parents yet downplayed by nurses themselves.

Nurses' views on parental resistance

Nurses interviewed for this study were, not unexpectedly, just as socialised in the ways of the institution as the doctors were; only in their case, there was an overlay of practices that were based on a different type of habitus within the same (medical) field.¹³⁷ For instance, nursing understandings of the causes of parental resistance fit reasonably well within the views of the doctors discussed in Chapter Seven or as presented in the literature (Chapter Three) although

¹³⁷ In relation to resisting parents and the roles of those who must respond to such resistance, a great deal could be made of the relational field of the nurse within the wider field of medicine. According to Bourdieu & Wacquant (1994), it is only possible to grasp the structure in a specific field by studying its history, the tensions and conflicts between the field's different positions, and by studying the field's relationships to other fields.

nurses were reluctant to label resistive parents as being necessarily ignorant, neglectful or abusive. Instead, the term 'difficult' was employed again and again to cover a multitude of behaviours in parents that do not readily conform to nursing expectations.¹³⁸ For nurses, the use of the label 'difficult' in conjunction with the concept of resistance of any kind (i.e. mild or more overt) seems to cover a wide range of general possibilities when dealing with resisting parents. For instance:

In general it would be, you know, you would use words like I suppose "difficult" or "highly stressed" or we'd be very rude in generalising about their culture; or not their culture, but their where they're from, their background. But it would be very, very rude about if they are sort of from [a city district] and they don't want to be putting down things like this disease, or they don't want that... (N1, p. 17).

'Difficult' in this extract is associated with a geographical and social background, which in turn related to a particular cultural perspective. It is an example of Bourdieusian 'difference' and the ease in which one group or class quickly labels another if there are noticeable differences in social capital and habitus. Nevertheless, there are clearly class differences between some nurses and the parents that emerge as resisting parents. For instance, as one interviewed nurse maintained:

...the classic ones are parents who are really highly educated and from perhaps a corporate world is a good example. They have a postal code which is X and Y and some who are very much well read and middle class and ...who feel that they know an awful lot and that we're taking it completely out of their hands. And from simple things like incubation, ventilation to giving antibiotics we've had such parents resisting those things (N1, p 5).

In the following extract, another nurse uses 'difficult' in similar ways, indicating a degree of interconnectedness between nurses that is based upon shared understandings about ways of communicating and working together:

[Interviewer] *What about the parents - do they [nurses] share notes on the parents - do they say "these parents are difficult" or "there's something about these parents that's not right..."* [Nurse] Yep, all the time, all the time. I think it's, I don't know if its human nature but it's certainly the nature of a working relationship with your colleagues I suppose in a way (N3, p. 21).

However, irrespective of the use of the term 'difficult' parents, nurses still have views on the causes of parental resistance. These views are similar to those expressed by doctors being focussed on parental religious beliefs, psychological factors or cultural differences. For instance, in a connection to both established literature and media viewpoints, one nurse connects notions of child neglect to the religious belief systems of the parents but perceives those beliefs to be outside of the mainstream:

[Talking about the Moorhead case] You know that's interesting because I actually think they... that was gross neglect. I think that the treatment that was needed for that, for their baby, was non dramatic and it would have, you know that child, all it needed was an injection. And um they

¹³⁸ According to Darbyshire (1992), role negotiation between nurses and families is often 'problematic.'

basically did neglect, failed to meet their child's needs really ...I think that they were really influenced by their religious beliefs and there's always people who will take their religious beliefs to the extreme ... (N5, p.8).

The following nurse interviewee suggests that parental anxiety is a recognised cause of parental resistance that contributes to their 'being difficult'. This nurse explained that resistance was associated with 'character' traits that were either acceptable or unacceptable. That is, the nurse seems to find those parents who exhibit clear signs of stress or apprehension to be more acceptable than those parents who are not considered to be distressed, or those who belong in the category of being disliked by other nurses because they are being 'difficult':

But yeah, I think it's probably just a character thing. But sadly, I mean there is that distinction between those really difficult parents who everybody dislikes intensely and those parents who are very, very stressed and very, very apprehensive ...But you can kind of understand it, and there are always those parents in that category; they always calm down, they always realise what's going on, they always can calm down if you put yourselves in their shoes (N1, p.20).

Another nurse interviewee mixed the 'causal boundaries' of parental resistance by offering an explanation that featured both a cultural and a psychological emphasis:

Well a terribly ethnic one I have come across in New Zealand is an anxious Asian parent ...which was, I found, very derogatory in the understanding of the parent.[Interviewer] *What would be the cause of such anxiety then?* [Nurse] I think it's cultural. Children are important to them and I think as parents, yes, they might tend to worry more than others, but it's just part of the culture. It shows how important a child is to them (N2, p.3).

All nurse interviewees for this study discussed cultural issues in relation to parental issues or resistance practices. Indeed, it was probably the most frequently mentioned aspect of causes of parental behaviours and most likely reflects the degree of time and effort that nurses put into dealing with families in the health care institution. However, in the following excerpt, it's not specifically the parents who become labelled as being 'awkward' or 'difficult', but an entire ethnic group. In this regard, the differentiation between 'we' and 'others' returns yet again:¹³⁹

I would say it's very cultural. Many European parents often seem slightly more accepting and more understanding and we have issues sometimes of Asian parents who particularly find it very, very difficult. I've had a case quite recently where the parents fail to accept that the child won't be ok. I'd say 50% of them find it very hard and will be given time to actually to assimilate the information and to make a decision. Yes, so, some of them find it really, really difficult (N1, p.3).

Connecting nursing difficulties to Asian parents was quite noticeable in many of the interviews with nurses, and it occurred to me that the 'otherness' of Asians was an example of a more exotic and recent 'otherness' which nurses had to work through in their practice.¹⁴⁰

¹³⁹ See previous discussion concerning 'otherness' in Chapter Five, p. 137, 141; Chapter Six, p.147; Chapter Seven, pp. 187, 191-192..

¹⁴⁰ I.e. more exotic than the commonly quoted and familiar 'Pakeha-Maori' otherness, or the European-Polynesian otherness, both of which are long established and well researched in New Zealand. For a more detailed account of Maori-Pakeha relationships in New Zealand, see Campbell, 2005; King, 1999; Scott, 1986: or for discussion concerning Pacific Islands/Polynesian-Pakeha relationships, see Graves & Graves, 1973; Jameson, 1997. For a complete overview of settlement and multi-cultural relationships in New Zealand, see King (2003).

Thus, as earlier indicated, nursing suggestions concerning the causes of parental resistance (religious beliefs, psychological factors, and cultural differences) were similar to those reasons offered by doctors, and the established literature. Nevertheless, it was in the processes of identification and response that differences between physician and nursing approaches to the management of parental resistance were noted.

Discursive themes in nurses' responses to parental resistance

It may be recalled that the medical habitus was perceived to be an integral part of 'doing medicine', such as the use of medical language and specialised equipment, doing 'consultations', making medical decisions, offering treatment, and giving orders to other health care workers. However, a nursing habitus was found to be less clear and certainly less demarcated. Even in examining the norms of the nursing field in relation to decision making and parental behaviours, the interviewed nurses showed a reticence to comment beyond what they perceived to be their ascribed role and/or their professional boundaries.

The nursing field and habitus

The nurses interviewed for this study, regardless of several years in practice, their status within the nursing hierarchy, or the various manoeuvres over decades to professionalise nursing, reflected an awareness of their position in the overarching medical hierarchy, which (partly by their own accounts and partly by the emergence of inconsistencies and 'silences' in the narratives) was lower than that of the doctors. There is a similarity in the nurses' responses to their role in the care of a seriously ill child, and their relationships with parents that calls to mind a characteristic associated by Bourdieu (1984) with working class respondents, namely: that their interviews were imbued with a sense of powerlessness or a "resignation of the inevitable" (p. 372). Indeed, nurses' perceptions of their position in the hierarchy clearly reflected both an in-between and a subordinate role not only in the health care system, but in society as well. This reflects Lupton's (1994a) observations:

Nurses working in hospitals must deal with professional conflicts over responsibility for the patient, negotiate struggles for power with physicians and contend with sexism and paternalism on the part of the doctors and patients (p. 121).

The power difference between nurses and doctors relates directly to differences of gender, social class and status, and the type of work that each performs. These significant differences are, as Bourdieu (1984; 1988) implies, because of a considerable and unmistakable difference between cultural and economic capital (which is higher in medicine and lower in nursing). Subsequently, nursing exhibits less disciplinary and healthcare prestige, and considerably less status within society at large (Chiarella, 2002). This is because in the work that nurses do, the social class distinctions between physicians and nurses emerge. Nurses attend to the minutiae of the needs of their patients in daily living and care based activities (such as hygiene needs, 'toileting', delivering nourishment and prescribed medicines, attending to clerical requirements,

and carrying out the doctor's orders) while doctors attend to the overall management of the patient, including diagnosing, prescribing of (medical) treatment, performing surgical interventions, and making key treatment decisions. Lawler (1991) takes this analogy a step further when she notes that nurses are associated with 'dirty work' such as washing patients' genitalia, assisting with bedpans, removing blood, vomit and faeces and even participating in the preparation of corpses. Such work is largely alien work to physicians who, to take the analogy further, only perform 'clean work'.

Thus, the habitus of physicians is 'doing medicine' and the habitus of nursing is 'doing nursing'. Both are aimed at a comparable end but are not seen as activities that share equal professional status either within the healthcare institution or society. Gendered stereotyping of nursing (Witz, 1994), along with perceptions about subordination to doctors, low academic standards, limited career opportunities and poor pay and conditions have all contributed to this impression (Brodie, Andrews, Andrews, Thomas, Wong & Rixon, 2004). There is also some evidence that supports the view that both medicine and the health care industry have sought to block nurses and nursing from achieving the desired level of professional status (Friss, 1994; Tully & Mortlock, 1999). Within nursing itself, there are numerous 'thwarted nurse' stories that support the lack of professional autonomy and involvement in (healthcare) decision-making opportunities for nurses. Some of these stories maintain that nurses are often treated badly by physicians and with disrespect (Cox, 1991; Greenfield, 1999; Manderino & Berkey, 1997; Sibbald, 2001; Spreen-Parker, 1990; Rosenstein, 2002).

Yet, an analysis of the material gathered from the nursing interviews in this study indicates that although there is some talk that concurs with the above overview of nursing's general status, there is also evidence to show that nurses play a significant part in the lives of parents and their seriously ill children.¹⁴¹ It is evident from the analysis that follows that nurses do play a role which is different from the discourses and practices described by the physicians (see Chapter Seven). Differences also exist in the relationships and power bases between nurses and the parents of the seriously ill children. Just as the medical field and habitus proves difficult for parents, nursing practices may have a similar effect. As Wilson (2001) implies, there remains the possibility that nurses, like doctors, use their knowledge within their own field to encourage parents to accept medical treatment through the establishment of friendly and warm relationships with parents, thereby minimising the possibility of resistance.

¹⁴¹ As was already maintained in Chapter Six.

In this thesis the nurses' narratives on parental resistance loosely match the main themes identified by Varcoe et al. (2004) which now serve as a guide for framing the following examination of discourses about nursing as an 'in-between' occupation. Ideas about nursing as a subordinate profession that is caught between 'old professionalism and 'new professionalism' are also used to explain the ways in which nurses perform their practice providing a link between themes presented in the following sections of the chapter.

Nursing as 'in-between' in parent-physician disputes

Bishop and Scudder (1991, 1996) argue that nursing is an in-between occupation, and maintain that nurses are positioned "in-between their own values and those of the organisations in which they worked, in-between their own values and those of others, and in-between competing values and interests" (p. 317). The discourse of 'in-betweenness' shares some of the characteristics associated with liminal states¹⁴² which has been used to "illuminate the in-between period, location, and experience of transition within more contemporary cultural and community contexts" (Cook-Sather, 2006, p. 111). In nursing, it is a state that has been associated with nursing's longstanding and close involvement with medicine, which is itself traceable back to the emergence of the positivist/scientific approach in medicine in the nineteenth and twentieth centuries.¹⁴³ This involvement has always been somewhere between being a skilled 'handmaiden' to doctors, an altruistic carer of patients, and an obedient worker lead by an assortment of managers (Chiarella, 2002; Reverby, 1989). Its legacy has therefore been felt right up until recent times, and arguably is still felt today because nurses are not fully recognised for the professional care that they deliver. For instance, doctors and nurses still do not share authority equally (Adamson & Kenny, 1993; Gianakos, 1997; Grunstein-Amado, 1992); doctors still tend to dominate decision-making processes, especially ethical ones (Melchert, Uden, & Norberg, 1997; Wilkinson, 1988); nurses still have difficulty in using their knowledge and values in a climate of fiscal and managerial constraint (Ketefian, 1981; Yarling & McElmurry, 1986), and overall, nurses still need to provide patient care within a context of rules defined by others (Hutchinson, 1990; Wuest, 1994).¹⁴⁴

Yet for all the above contextual issues that face nurses, Bishop & Scudder (1996) describe the in-betweenness of nursing as a central part of the "day-to-day care through which nurses foster the patient's well-being by bringing together (1) the physician's plan for medical care, (2)

¹⁴² Which, in anthropological and sociological discourses, implies a state of 'betwixt and between' more usually identified with rites of passage within a given society (Turner, 1979; van Gennep, 1960).

¹⁴³ As previously considered in Chapters 2 and 7.

¹⁴⁴ There are numerous 'constraints of nursing' arguments in support of this overall position; see Gordon (2005).

the institution's policies and resources, and (3) the patient's view of a good life" (p. 30). However, being in a position to do something and being able to do it is not necessarily the same thing.¹⁴⁵ Nevertheless, Bishop and Scudder (1991, 1996) and others (Benner, 1984; Benner & Wrubel, 1989; Witz, 1994) maintain that nurses' contribution to society is in a role that is complementary to that of the patient rather than subservient to the doctor. But can the nurse in a complimentary role support both physicians *and* the parents of a seriously ill child within the health care institute, especially if and when one of the two parties is either resisting or refusing further treatment? Rather than adopting an either/or position about the relative merits of nursing's in-betweenness in this instance, it may be more productive to explore it as a set of constantly shifting and transitory discourses and practices that contain within them both the uses of power and resistance. An example of a shifting and transitory discourse is offered in the following nurse interviewee's attempted to 'mediate' between the two parties. One of this nurse's methods when confronted with parents who showed early signs of resistance was to work more closely with the parents; and as physicians had done in the previous chapter, to re-examine parental understanding:

... it's going back to make sure they [the parents] understand what's actually been said and then say to them again "do you understand what this is?" And actually I will talk about, for instance, about a lumbar puncture in another way, [like] "did you really understand that this is what it is?" ...You know that type of thing ...it's also very important for them. Once again this is where we're at - how do you [parents] think about that type of thing? I can't speak for all nurses of course... (N3, pp.10-11).

This excerpt suggests that nurses, like physicians, perceive one of the causes of some parents' resistance to be a matter of misunderstanding medical wishes resulting from lack of information. Offering detailed and objective information, making sure that parents understand the choices, and following families up *after* the physician has spoken to the family is therefore important to the above nurse. However, nurses not only work closely with parents and their sick children, but with doctors, and with other members of the health care team. In that role, the nurse is often in an ideal situation to coordinate and 'hold things together' through in-betweenness'. As Bishop and Scudder (1996) maintain: "The in-between position is a privileged one from which to foster cooperative moral decisions by all involved" (p. 31). For example, in pursuit of options for parents, another interviewed nurse draws out the value of the nurse's 'in-betweenness' in as much as she is able to respect and appreciate parental angst, and the vital

¹⁴⁵ Bishop and Scudder's are mindful of the fact that some nursing scholars still view nursing's in-betweenness as indicative of servility to physicians (as argued, for instance, by Benjamin & Curtis, 1992; Engelhardt, 1985; Sheard, 1980); or as a type of binary 'tension' with nurses caught between "the service ethic or the caring ethic of the traditional caring professions, and the business ethic of the new management and contract culture of the purchaser-provider internal market" (Thompson, Melia & Boyd, 1994, p.130).

notion of parental subjectivity whilst at the same time be a medical ‘supporter’, and a type of ‘mediator’ within the system; as she maintained:

I can't comment specifically but I do know once it starts getting a bit difficult... then all resources are pulled in to help them and I don't know whether it's all to do with convincing them that they should carry on, but its resources are pulled in ...the social workers the dietician and anyone they need. We tend to, and I suppose that this in a round-a-bout way isn't it, talk them into doing it, but it's also giving them support to help them make those decisions. [Interviewer] *Do you think in general though, the support people support the doctors wishes?* [Nurse] Well, I think they're just doing a good job for the family - I mean they're not going to go in there and negatively push something, they're going to go in there and try and give them the options both ways as far as I can see (N3, p. 11-12).

But, nurses do not necessarily share the view that the doctor is presenting, neither are they always present when “the (medical) options” are given. As the following nurse’s narrative reveals, a nurse may have her own private opinions, but is limited to the extent to which she is keen to share these opinions with the physicians. Instead, the nurse basically stands aside as the doctors take over:

Probably then you respect the parents wishes to an extent. But I think more often than not medical staff would go back and just reiterate what they've said and the reasons why they want to do this, but its still certainly up to the parents. And we have certainly not gone ahead, but looked at all options. Probably in that case we would give parents a different option to okay, or “if you don't want this test well then we would pretty much would like this child to stay in over night” - you give them a different road to take and that certainly has happened (N3, p.4).

The nurse suggests that the doctors may sometimes acquiesce to parental wishes, but it seems more likely that the doctors would promote their own position where possible because of their perception of their role as an advocate for the child.¹⁴⁶ However, when a nurse’s role as parental supporter *and* physician’s collaborator merge together within the ‘in-between’ circumstances of the nurse, considerable role confusion and hesitancy may result:

Certainly it all depends - the person, the place, and the back-up that you've got. Once again I'm not black and white - I have to take it as it comes, as whether the doctor was, what I know about this doctor, how that doctor got his judgment or... that's probably more so where I come from ...If though I truly wanted to stand up for something and later I had maybe a consultant to back me up and then a consultant [should be] doing it ...Usually because you'll often find the nurse walk out of the room and say to the next nurse, “he should be doing this”, or, “he should be doing this but he's not going to” ...and its really just a verbal back-up isn't it really because you're not always going to confront... [fade] (N3, p.19).

The previous narrative suggests the nurse may choose the easier path, and support the doctor, as indicated below; however, on some occasions the doctor may specifically ask the nurse for support:

[Interviewer] *Do the doctors ever come to the nurse and say these parents are being difficult, go and talk to them. Does that ever happen?* [Nurse] I suppose it does happen, but that nurse would have to agree that the treatment needs to be done as well. So if someone came, if the doctor had

¹⁴⁶ See, for instance, discussion on pages 78 and 84.

come to me and said you know, which he has, and I have gone back into a family and, like I say, reiterated what was said and made sure that they understand what it is, that's it (N3, p.21).

But does the nurse always wish to support the physician's decision, and what position does the nurse wish to take in such situations? When a nurse's position is in a state of continual flux or 'in-betweenness', i.e. neither entirely 'with' medicine nor entirely with parents, it is, as Foucault (1979) noted, embedded within "mobile and transitory points of resistance" (p. 96). In response to this dilemma, the nurse suggests in the following narrative that disagreements between clinical staff and parents are diffused and clarified through communication, suggesting that in order to side with parents, a rational and unemotional self is required - but only in the unlikely context where other health professionals are being emotional or irrational:

[Interviewer] *Have you ever been in a situation where you want to support the parents or whatever and your colleagues don't...?* [Nurse] Um, I can't think of an instance ...'Cause I've always talked with my colleagues and... I think if I had, I think I'm quite reasonable, so if I come to some sort of conclusion or I've wanted to stick with the parent, it would be because I'm not being irrational and others would be (N3, p25).

Nursing as 'caught between' resistive parents and physicians

Nursing exhibits a set of behaviours and beliefs that differentiates nurses from the larger medical culture of which it is considered a part (Yarling & McElmurry, 1986). Nursing is different from medicine because of the gender, class and occupational capital of its members (Bourdieu, 1984), although it also shares commonalities with medicine in that the members are numerous but subservient, technically well trained but dependent on others, and autonomous only within their own sphere of influence rather than across an entire system. Overall, the medical model is generally supported by nurses in their professional role when dealing with situations involving a seriously ill child and resisting parents, as the following nurse implies:

In my experience most nurses come down very, very hard in the favour of the medical model and very anti-parents in that situation when you take the rights of that child away. In situations where it's touch and go you know it's chemotherapy that's possibly not going to make a difference to the child's quality of life - that's really different - that's a very hard one to argue - that's when you really, really need to step into the parent's shoes and try and understand and have empathy for them I think (N1, p.7).

Varcoe et al. (2004) suggest that the nature of nursing as a profession means that nurses work within 'a mesh of interdependence' based on subservience to members of the medical profession and others rather than independent actions, which they found to be a cause of "tensions and conflicts in values" for nurses (p.321). In this research on parental resistance, where a high degree of medico centrism has emerged as a norm, it was a doctor rather than a nurse who provided an interpretation of the nursing role as being part of a team and acting as a family advocate yet at the same time supporting physicians who hold the power to decide:

I've worked very closely with nursing staff and I think that nurses are a key part of the team, and in making some of these...helping the families, assisting the families, in making some of these decisions. I guess that there are some reservations about objectivity for some nurses; not for most, but for some nurses I know where they feel very strongly that they're a family advocate rather than necessarily the child's advocate and I guess it's that balancing again, which is difficult And I think

also too sometimes they can be supportive. But the hard decisions come down to the doctor really. I think you know, the nurses can be supportive of what you ought to do, but it comes down to us signing on the line and writing the letter ... (D4, pp 7-8).

Hard decisions therefore belong to the physician's domain; while helping and assisting families as an advocate belongs to the domain of nursing. Yet, such advocacy may lead to difficulties for a nurse in a system where her/his role remains that of a subordinate of medicine caught between parent needs and medical desires.

Varcoe et al. (2004) maintain that nurses are 'caught' between various parties within the health care setting. The situations described by the nurses interviewed for this study appear to confirm this finding because they frequently expressed ideas that related to the expectation that they use their 'in-betweenness' to enhance the communication of ideas between doctors and patients (and/or parents of child patients) in the form of patient advocacy. Nurses perceived acting on behalf of vulnerable patients and/or their families as one of their key roles.¹⁴⁷ This aspect of the nurse's role reflects the 'betwixt and between' space that nurses occupy, but in that betweenness, there is an indication that nurses are expected to be allied to one party more than the other¹⁴⁸; and, as the narrative of another doctor suggested, represent the patient/family/parent as a type of 'go-between':

Nurses ...are less likely to engage in a debate about ethical issues I would have thought, generally, because they're probably not as critical on the decision making processes as doctors would be and therefore are less likely to perhaps, formulate an opinion about complex issues of dissension. Because they will tend, if there's conflict and dissension, nurses would often take the side of the family to try and understand them, to be a sounding board for them and to try almost a go-between if you like between them and the doctors (D3, p.2).

In the above excerpt the physician suggests that nurses are not expected to engage in ethical issues or decision making (which is seen as a medical prerogative), but they are expected to identify more closely with their patients and families, and be supportive of their needs and act as their advocates from time to time, but, when important decisions are made, the nurse is little more than a go-between. As 'part of the (medical) team' or not, nurses are expected to operate in a particular fashion on behalf of their child patients and their parents, but their input or advice

¹⁴⁷ As was the case in research performed in a large British tertiary paediatric hospital where it was found that nursing staff considered family wishes and family perceptions of patient suffering as significantly more important factors to promote in decision making than medical staff, who considered prognostic factors as most important (Street, Ashcroft, Henderson & Campbell, 2000).

¹⁴⁸ In research performed with Neonatal Intensive Care (NICU) nurses, the main findings showed that they saw their role in ethical decision-making primarily as advocating for the best interests of the infant and family, but while being primarily assertive in presenting their views, some nurses took a more passive approach (Monterosso, Krisjanson, Sly, Mulcahy, Holland, Grimwood et al. 2005, p.108).

could be overridden at any time.¹⁴⁹ Nurses are therefore ‘caught’ between doctors and parents, and unable to contribute directly to matters relating to decision making themselves.

Even within relationships between nurses and physicians, power is capable of being both constraining *and* enabling, as an instrument of repression *and* a means of freedom, depending upon the abilities of those using it to produce knowledge which could be perceived as ‘truth’ (Foucault, 1979).¹⁵⁰ For those nurses that accept and support the medical model (and also their ‘in-betweeness’) there may be adequate reward in the form of acceptance and support from members of the medical profession, which counterbalances any potential resentment from parents. In this sense, nurses are involved in relationships of power that are ‘strategic games’ that are played by all, in conditions where power fluctuates between the players:

We must distinguish the relationships of power as strategic games between liberties – strategic games that result in the fact that some people try to determine the conduct of others – and the states of domination, which are what we ordinarily call power (Foucault 1988, p. 19).

Nurses working within a medical setting often feel compelled to play by the rules of the game and live with the possibility of contradiction or confusion over their role within it (Chiarella, 2002). Such confusions illustrate the difficulties with the in-betweeness of nursing in cases of parental resistance; the nurse either agreeing with the medical position but attempting to support or advocate for the parents, or disagreeing with the medical position but being unable to adequately respond from a nursing perspective by either supporting a nursing position or the parents; for instance:

[It became] a battle of wills in so far as saying that this doctor, I suppose, had really decided that this child really did need this treatment and was quite adamant that they should ...I do remember a case that it was quite adamant and they just about were going to start ...you know this Paediatrician or whoever he was, and the Registrar was quite adamant that this needed done. And I think from my experience when I’ve seen it happen [parental resistance], once or twice in the past, it’s because the medical staff have been that adamant about it. I think I’ve probably been more on their side that it should be done too because they are seriously worried because we have been able to give options before and there were ways around it. If it was a mild case I probably would have stood up but over the cases that I’ve been involved in it’s been quite serious and the child probably then does need to be treated (N3, p.7-8).

¹⁴⁹ Such a state of affairs in the daily decision making practices of nurses and doctors is reflected in research. For instance, in an examination of ‘discrepant attitudes about teamwork among critical care nurses and physicians, Thomas, Sexton & Helmreich (2003) found that only 33% of surveyed nurses rated the quality of collaboration and communication with the physicians as high or very high, but 73% of physicians rated collaboration and communication with nurses as high or very high; these findings therefore suggests that from within the perspective of the nurses’ habitus and operational field, collaborative relationships with physicians were not very good.

¹⁵⁰ For Foucault, “...power is not always repressive. It can take a certain number of forms. And it is possible to have relations of power that are open” (Foucault, 1980g). Indeed, power could appear in multiple forms, i.e. as a form of an ideological manipulation, rational argumentation, moral advice, or economic exploitation, and many more, but in every case power may promote positive or negative results.

In relation to resisting parents and the roles of those who respond to resistance, a great deal could be made of the relational field of the nurse within the wider field of medicine.¹⁵¹ As previously maintained, the nurse is ideally placed to intervene on a more personal and intimate level than any other health care professional (Benner, 1984; Benner & Wrubel, 1989). That nurses do not perceive their role in influencing parental decision making to be as powerful as the physicians' role (as is maintained in later discussion) in situations involving parental resistance is therefore of particular interest. This is because a case could easily be made that the nurse, of all health care workers, is the most ideally placed (i.e. as the 'in-between' health care professional) to intervene at the right moments during the care of a seriously ill child to adequately respond to parental anxiety, or culturally based misunderstandings, or lack of knowledge, or religious misgivings about a proposed treatment (Bishop & Scudder, 1990, 1991). That the nurses interviewed for this research project do not appear to do so may, at least in part, be related to a prevailing doxa¹⁵² that only doctors take responsibility for negotiating proposed medical treatments with parents of seriously ill children, and that there is no particular place for nurses to lead such negotiations. Instead, when confronted by resisting parents, some of the nurse interviewees at least saw their role as a medical supporter *above all else*, and to justify this, fell back on the collective institutional power of medicine rather than a nursing power base or any organised nursing resistance to the medical position:

...certainly that business of them having to hand over and explain their decisions, especially when they've [the parents] just been told, maybe the day that this is protocol, you [the nurse] must do it. [Interviewer] *By protocol you mean the medical protocol in that view for the standard treatment...* [Nurse] Yeah, or for this treatment; this is what we do. Bang, bang, bang and bang (N3, p23).

The same nurse as above continues later with an argument based on the notion that in the medical hierarchy, everyone has 'to follow the rules' irrespective of their own position or the particular situation:

Sometimes I think - to tell you the truth - sometimes I think the junior doctors ...are pig headed about a treatment and just have to go through with it...And that I've seen many a time... because they had to (N3, p 23).

The notion of 'because they/we had too' causes problems for the nurse, because she must wrestle with the problem of following the treatment protocol whilst at the same time

¹⁵¹ Bourdieu maintains that certain habituses operate as symbolic and cultural capital, and therefore qualify individuals to advance in given social fields. The 'boundaries' (points where group similarities end and differences begin) of any particular field in terms of the nature of the capital present and who and what are drawn into its domain are not fixed but are strongly contested by those within the field (Wacquant, 1989).

¹⁵² A profession's doxa is very much 'docta ignorantia', or an attitude and value system that is deeply entrenched, even if it is lacking in awareness of the principles of its own origin and development. As Bourdieu (1982) notes, in a given field, the 'players' accept the premises of that field without hesitation and accept its basic premises as givens. It could be argued, nurses accept their secondary role in health care, in medicine, and in responding to parental resistance, because they have accepted the medical field's doxa and do not even perceive any other possibilities within that field.

experiencing his/her own doubts and/or divided loyalties. That is, there is evidence in the nurses' texts gathered from the interviews that a nurse may side with the doctor's view, even though she does not share the same view:

...there's a protocol in place for instance down in [a hospital department] at the moment, I think it might still be there, of giving [a drug] that in my experience doesn't work as well as [another drug]. Because I'm the nurse that gives it, I'm the one that sees that it is but it's spat out at you; it's not taken, dar, de, dar de dar. But they stick with it and they stick with it and stick with it and it doesn't work but they stick with it because someone's doing, the consultant's doing an audit - so this has to be done. It goes right against the grain, so mmm (N3, p.24).

Nursing power and control depends upon a significant degree of societal acceptance, achieved through their association with all things medical. In regard to the 'nurse's view', there may indeed be such a thing as a 'nursing gaze' which exists in ways not dissimilar from 'the medical gaze'. However, the debate continues whether such a gaze exists that is distinct from medicine (Ellefsen & Kim, 2004), or as an adjunct to the ethos and logic of the dominant medical model (Lees, Richman, Salauroo & Warden, 1987). The latter seems more likely because it is certainly the case that in recent years, nurses have been encouraged to concentrate even more heavily on 'advanced clinical skills' such as improved assessment skills and 'nursing diagnoses' (Doenges & Moorhouse, 2003), making better use of their time in more efficient ways, and generally emulating the more accessible ways and means of the medical profession (by becoming 'nurse prescribers', for instance). Critics of these trends would argue that nursing is trying too hard to 'blur the boundaries' or to modify the great traditions within nursing to be more like those of the medical profession (Gordon, 2005). In this regard, it is sometimes thought that nursing is a profession that is caught between two professional discourses – the 'old' and the 'new'.

Nursing as operating between old and new professionalism in parent-physician disputes

Independent professions are characterised by professional autonomy; a clearly defined, highly developed, specialized, and theoretical knowledge base; control of training, certification, and licensing of new entrants; self-governing and self-policing authority, especially with regard to professional ethics (Tully & Mortlock, 1999).¹⁵³ This signifies control over remuneration, social status, autonomous or authoritative power, and a commitment to public service (Pratte & Rury,

¹⁵³ The traditional view of a profession was largely developed by Abraham Flexner (1915) and later re-examined and refined by others such as Turner (1979) and Abbott (1988). In his examination of 'universally accepted' professions (i.e. law, medicine, architecture, engineering and the clergy) - which was itself prompted by a desire to standardize education and to establish scientific medical education and practice - Flexner described criteria for characterizing professions and concluded that: "professions involve essentially intellectual operations with large individual responsibility; they derive their raw material from science and learning; this material they work up to a practical and definite end; they possess an educationally communicable technique; they tend to self-organization; they are becoming increasingly altruistic in motivation. . . ." (Flexner, 1915).

1991). Yet, nurses are not perceived by society at large to hold the same amount of prestige and power as physicians (Lupton, 1994a). That is, it is usually recognised that they hold some sort of power, i.e. over their patients, amongst each other, and even within society, but that the origins and development of that power owe a considerable debt to the role of medicine in society, and nursing's lingering 'assistants to physicians' image. As a result, challenges have arisen to the 'masculine bias' that has lingered from Flexner's (1915) seminal work on professions almost a hundred years ago, through an examination of the characteristics historically linked with nursing, which were (and still are) predominantly feminine and collectively orientated, such as nurturing, caring, personal, involved, altruistic but servile (Wuest, 1994).

Conflicts about role and responsibility bring to mind one of Varcoe et al.'s areas of concern about the 'many layers of conflicting loyalties' that predominate for nurses in their relationships (which in this thesis are between parents and physicians):

As they worked the in-betweens, nurses did not always take action when they encountered conflict. They spoke of 'choosing your battles', and sometimes choosing to 'let it go'. They described weighing the risks and benefits of taking action, weighing the seriousness of a situation, and weighing their authority relative to other players in a given situation (Varcoe et al., 2004, p 321).

There are connections between the issues identified in this extract and the narratives of nurses interviewed for this thesis. In the Varcoe et al. study, nurses were aware of the need for them to take part in health care related decision making, but historically, socially and contextually situated factors hampered them from doing so. Nurses strategically negotiated the margins or the in-between areas in an attempt to do the 'right thing' and by doing so argued that their moral identity and agency was profoundly shaped by contextual/ organizational forces such as physician and institutionally based requirements. That some nurses perceive such relationships in the health care context as a type of professional or strategic 'game'¹⁵⁴ that they often have to either play or attempt to avoid is therefore of considerable interest.

The background or liminal role of nurses tends to colour discussion about nurses' responses to parental resistance, as there were times during the nursing interviews when it was uncertain whether or not nurses were involved in any of the decision making discussions that may have lead to dissent and/or disagreement between parents and physicians. This notion was eventually put to one side during analysis of the nursing texts as it was realised that nurses were involved,

¹⁵⁴ Stein (1967), for instance, saw the nurse-doctor relationship as a type of 'game', concluding that: "The game is basically a transactional neurosis, and both professions would enhance themselves by taking steps to change the attitudes which breed the game" (p. 703).

but in significantly different ways to physicians.¹⁵⁵ The replies of the nurses tended to represent a supporting role for nurses who are caught up in between the parameters of ‘old professionalism’ and ‘new professionalism.’

New professionalism, as a reaction to the long established ideas of ‘old professionalism’ (Abbott, 1988), is based on a form of partnership between a professional and a client (Tully & Mortlock, 1999; Stacey, 1992).¹⁵⁶ It reflects an emphasis on an interactive and reflective partnership where the values of both parties are recognised (see Figure 8, over page). In recent years, nursing has incorporated elements of old professionalism - as in the recent return to the professionals as experts through the development of a (scientific) knowledge base (Doenges & Moorhouse, 2003) - whilst at the same time promoting a type of new professionalism within their own profession. That nurses have accepted a position somewhere between ‘old professionalism’ and ‘new professionalism’ (which is itself a form of in-betweenness or liminality) where the view of professional work is neither fully accepted nor fully rejected is therefore ironic.

‘Old’ professionalism	‘New’ professionalism
Support hierarchical relations	Interactive relationship between professional and client
Primacy of scientific knowledge which positions professionals as experts	Reflective use of knowledge and experience
Paternalistic	Partnership – negotiated outcome
Knowledge and absolutism	Emphasis on interpersonal skills
Knowledge as value free	Knowledge as value laden

Figure 8: Old professionalism-new professionalism.

¹⁵⁵ Such is the confusion between the two perspectives. For instance, in an extensive study across seventeen European countries, physicians were asked to state their understanding of nursing involvement in end-of-life decision making (EOLD). It was concluded that: “Physicians perceive nurses as involved to a large extent in EOLDs but not as initiating the discussion. Once a decision is made, there is a sense of agreement. The level of perceived participation [of nurses] is different for different regions” (Benbenishty, Ganz, Lippert, Bulow, Wennberg, Henderson et al. 2006, p. 129).

¹⁵⁶ See also discussion on models of medical decision making, Chapter Three, pp. 79-82.

The confusion over the exactly where nursing 'fits' in professional terms is partly illustrated in the following excerpt from one of the interviewed nurses when asked about the degree of professional inclusion that nurses had when faced with resisting parents:

It depends which doctor. I can see that the doctors in [another country] were excellent with discussing with the nurses. The consultant was really, really good in involving the nurses in decision making with regards to parents who might pose a bit of a challenge to care. Maybe some of the consultants in England wouldn't and I'd say in New Zealand it's very much up to the individual doctor (N2, p.8).

This reply incorporates a geography of 'here and there' that speaks to the politics of location (Phibbs, 2001)¹⁵⁷, enabling this particular nurse to perceive her/his role differently according to her/his understanding of how hierarchies operate in different medical fields (i.e. England v New Zealand). The nurse describes an epistemological field where categories of knowledge follow a particular sequence within the dominating organisational structure. The nurse's reply also indicates that the perceived place of the nurse is as the one who waits to be involved rather than is proactive, and who responds according to the direction of the doctor rather than out of a perceived understanding of an inherent duty. Another nurse offers a similar picture:

I think most decisions are made by the medical staff and then they would really go and discuss with the family what they want to do...and actually probably not get their permission but they would only discuss consent. If the parents sort of like said to them "oh actually, I don't agree with that. I don't want that to happen" they wouldn't go in and say, "do you mind if we do such and such?" It would be, "this is what we're going to do..." [Interviewer] *And so they (the doctors), they get together and talk about this child's case and make a decision?* [Nurse] Yes. [Interviewer: *And then they go and present it to the parents?*] [Nurse] Yes (N5, p.1).

In the above narrative, the nurse suggests that doctors sometimes plan ahead and present parents with a *fait accompli* in regard to the medical position and decision about a child's treatment. The nurse also indicates that nurses *and* parents are minimally involved in treatment decisions, and to an extent, (collective) decisions are made *before* negotiations with parents, the nurse being at best a supportive bystander. These extracts may be read as examples of 'old professionalism' at work, and also as illustrations of nursing liminality, in as much as the nurses involved perceive their role to be 'on the fringes' of medical activity. In short, in these narratives nurses are marginalized; they are not taking part in an equal 'partnership' (as in 'new professionalism') with either doctors *or* parents. However, there is some evidence within literature that nurses do perceive themselves to be in a greater partnership role with their patients and/or parents (Garel, Gosme-Seguret, Kaminski & Cuttini, 1997).

¹⁵⁷ "In its hierarchical movement, location insists on a taxonomy of experience. One doesn't have to scratch the surface very deeply to find that class, race, and gender have a lot to do with whose experiences are on top. The classification of experience, moreover, is indivisible from what came before and which knowledges stand as previously sanctioned" (Probyn, 1990, p.184)

The dominance of a male, patriarchal standpoint of the medical profession continues to ensure that nurses remain largely unrecognised as health care professionals capable of greater involvement in the 'medical domain'(Wuest, 1994). According to Rosenstein (2002), this is because the medical domain is still one where "old-school" traditions that include gender bias (that assigns a subservient role to women) remain, and where the disruptive behaviour of physicians (who bring a great deal of economic and cultural capital to the hospital) goes largely unchallenged. It is also the domain where senior physicians underestimated the significance of the difficult situations they sometimes place nurses in, and/or are reluctant to counsel their more junior peers. Nurses still exhibit considerable anxiety over the already complicated problems (of their points being either ignored or overridden) that they experience when advocating for their patients or relatives (Fleming, 1991), and still maintain that in, for instance, ethical disputes, it is the nurse and not the physician, who must often compromise her/his ethical position (Grunstein-Amado, 1992). Nurses maintain that they are organisationally caught in an "in-between" or liminal situation that may hamper their full involvement. The nurse's role in cases of parental resistance to medical treatment is a difficult, confusing and often contradictory one. Nurses are aware that the child and his/her parents are at their most vulnerable when facing a life threatening diagnosis, and therefore they are obliged to seek ways to respond to this vulnerability. In the face of medical objectivity, nurses (and clearly parents) are subject to a degree of medical and institutional surveillance and control (Armstrong, 1995) that tends to not only restrict nurses' views, but shape them as well.

Nurses' responses to parental resistance

In the interviews with doctors and the nurses, it seemed that nurses' involvement in parental decision making was marginalized because the doctors did most of the negotiating and responding with parents. However, the previous discussion about the positioning of nurses by some of the parent interviewees, combined with the description of nurses as frequently being in an 'in-between' or liminal state, suggests that nurses are playing different roles to physicians in their responses to parental resistance. What follows is an overview of the nurses responses to parental resistance that illustrate the discursive elements that are the 'in-between' nature of nursing, the ebb and flow of power and resistance, and the diversity of nursing responses to parental resistance.

The nurse as a medical collaborator

One theme that tended to reoccur in the responses of the nurses interviewed about their involvement with resisting parents who might be, or were 'difficult', was that of the nurse as a type of medical collaborator. In this role, the nurse occupies a space as an associate of the work of medicine rather than as professional partner. This role closely matches Bishop & Scudder's (1990, 1991) notion of the nurse as the 'faithful executer of sound medical regimen prescribed

by physicians.’ For instance, the nurse works as a ‘preparer’ and preliminary ‘assessor’ for the doctor’s visit, and then ‘follows up’ after each consultation from doctors to smooth the path for further medical interventions. On admission to the unit for example, the nurse usually went to see the child and parents ahead of the doctor to record basic admission information concerning the child’s present health status (i.e. age, height, weight, blood pressure, temperature, and other observations). The nurse’s role as a ‘medical preparer’ gathering routine patient information before the doctor assesses the patient is expected of nurses (Rosenstein, 2002). In this first contact, the nurse also performs a preliminary psycho-social assessment of the family as well. In doing so, paediatric nurses generally weigh up the parents’ demeanour, and performs a preliminary assessment of their possible readiness for medical interventions. Hence, the nurse will often have first contact with the child and parents, and therefore develop the first impressions of them as a family group:

...the nurse would assess the child and do a set of vital and a visual assessment and take a brief history from the parents and then document that and then go back to the doctor and say this is what I’ve found and then the doctor would go and examine the child. [Interviewer] *Right, and then the doctor would...?* [Nurse] They would decide whether they need to do, bloods, lumbar punctures... (N5, pp 1-2).

Early contact enables the nurse to perform preliminary recordings and assessments on the child patient, and to assess the parents as well, subsequently relating these early findings on both child and parents to the doctor *before* he goes to see the family. In this way, the nurse acts as a ‘scout,’ often passing on initial observations (i.e. physical, psychological or social) to the doctor (which is also an example of the nurse as a type of ‘go-between’). The nurse would usually end her parents’ assessment with some sort of indication that they are to expect a visit from a doctor in the near future.

Later, as the treatment for the child is instigated and performed, there still remains periods before the doctor’s subsequent visits where the nurse continues to feed family related information to the doctors:

There’s a period on a ward before they [the doctors] go in and see patients and it will be during that time that any issues would be brought up and discussed between the nurses and doctors and that’s the opportunity for the nurses to fix them up (N2, p.7).

As a result, the nurse uses the ‘in-between’ times to support not only relationships between themselves and physicians, but also between themselves, their patients (families) and physicians as well (fixing things up out of sight of the parents). These actions are associated with the nurse as a sympathetic patient/parents carer and/or advocate, which is a nursing role that is also reinforced by physicians.

According to the following physician’s narrative, the involvement of the nurse reflects a type of ‘friend of the family’/early psychological assessor role, i.e. as a gatherer of information that the doctor may find useful when dealing with the parents that the doctor may not ordinarily be able to easily extract. The doctor suggests that if nurses has an equal status with physicians

and operated in a more clinical and medically orientated fashion, then they may not be able to access this information. In preparing the ground for the doctor by seeing the child patient and parents, the nurse fulfils the roles of messenger, go-between, sympathetic carer and medical collaborator:

Well I personally had situations when nurses have come out to me when I've been about to go in to see the family for the first time when they're had an hour settling a child into the ward and talking to the family. And they've come out and have said 'we're going to have real trouble here'....And so they pick up like; nurses often provided with information by the family that the family will not share as quickly with doctors. There's certainly, there is a different professional acceptability I think to a lot of staff. Like a lot of parents won't ask the doctor a question, they'll ask the nurse a question after the doctor's left the room. So you know, a family may say to the nurse, 'look we have a very strong religious faith so don't like being here, we're, in the past our religious faith has always helped us out very well and you know, that's right and nurses will come out and tell us that (D1, pp.3-4).

Thus, in conjunction with preparing the ground for the physicians, the nurse fulfils other useful roles as well; i.e. in situations where early signs of parental resistance are noticed by the nurse, the nurse also serves as an 'advanced scout' for the medical staff. In this aspect of the nurse's response to potentially resistive parents, whether it is a nurse's viewpoint or a physician's one, the nurse's role is therefore remains secondary to that of the doctors. It follows that the nurses' responses in their interviews should be seen as a reflection of their perceptions of their perceived role within the dominant discourse that is medicine.

The nurse as a 'team player'

The following statement indicates the secondary role of the nurse as a 'team player' when confronting 'difficult' or resisting parents. The nurse implies that she is 'waiting in the wings' preparing to respond to the decisions that have been instigated by doctors:

Well pretty much it's going to come basically down from the medical staff, often here we find the medical staff have come to some sort of decision as to what they're going to do but then they do tend to talk to if there's senior staff around and discuss which way of going about it. I tend to find that anyway. Sometimes its divided and that is what's going to happen and you pretty much go along with what's been decided unless of course its something you don't agree with. And in my past year if I haven't agreed with something that they might be going ahead with I'd certainly speak up and discuss it - talk about as to why (N3, p.2).

In this last excerpt, it is apparent that the nurse can be torn between 'going along with it' (and thereby siding with medicine and the institute), or 'speaking up and discussing it' (thereby siding with the parents). The nurse does not perceive it as her role to *lead* the debate with resisting parents about the desirability or otherwise of medical treatment. Instead, the nurse perceives her role to be a collegial one as a part of 'the medical team', ready to contribute when approached:

Primarily what we do is we, if things are that bad, the neonatologist will review the situation with another neonatologist and then the situation with the cot side nurse; and we actually are very fortunate to have family liaison nurses¹⁵⁸ who take a lot of stress on board in those situations (N1, p. 2).

However, the medically orientated, 'always ready to contribute role' extends into the 'go-between' role in certain circumstances, where the nurse might operate as an 'explainer' for the parents, by being a 'preparer' before, or as an 'interpreter' after the doctors' visit (where the nurse is either absent, a secondary contributor, or even silent):

Well to tell you the truth ...down where I work, the doctor may have decided or discussed this [a given problem] and as a nurse I'd be the next one popping in [to see the parents] and seeing if they understood. I may have been the first one to see these people anyway and probably told them this is the course that we usually take in this type of thing ...So may have eluded to it that this is probably the road we're going to take but let's wait and see what the doctors have got to say. They would go in and make their decision as to this is what we want to do; talk to the parents about it. Often as I would say, I would go back in again - typically a nurse would go back in again and would try and make sure that they understand the reasons why - you try (N3, p.3).

In the above excerpt, the nurse not only 'foreshadows' the doctors' imminent arrival, but 'prepares the ground' by eluding to what the parents might expect from the doctors. To ensure that the medical message was fully understood, the nurse even returns later to check that the parents had understood the message. There is also a suggestion in the above extract that the nurse considers the time when doctors first address the potential treatment of a seriously ill child with parents as being an important juncture for nursing input, to correct misunderstandings, confirm what has been said by physicians, and thereby to prevent future difficulties.¹⁵⁹ It is also evident that whilst physicians defer to other doctors for advice when faced with resisting parents (see previous chapter), nurses defer to the doctors ("*let's wait and see what the doctors have got to say*") or sometimes to other nurses (i.e. the family liaison nurse). In this fashion, nurses, like doctors, recognise and defer to the symbolic power of the collective wisdom of medicine. Thus, this nurse perceives her role to be one of monitoring parental response and as a way to support and reinforcement of the work of the doctor.

There is some evidence to suggest that nurse's role may not be an entirely passive one in all situations. For instance, another nurse suggested the following when talking about how a 'not for resuscitation' decision is made in relation to a child patient:

Usually that decision is only made once a family meeting is called, and the family meets with the consultant and the nurse, the primary nurse and the nurse from the community, social worker, maybe cultural support and if an interpreter is required, then through an interpreting service. The family is given information by the consultant; if the family has questions, if there are any

¹⁵⁸ Family liaison nurses operate in the spaces between primary, secondary and tertiary health care.

¹⁵⁹ There is research evidence (from a study performed in an American Pediatric Intensive Care Unit), to support the view that nurses are significantly less likely to agree that families are well informed and ethical issues are well discussed with them by physicians (Burns, Mitchell, Griffith & Truog, 2001).

questions, they're answered by any of the individuals there that perhaps is the most in authority to answer that particular question, but then the decision is made by the family... (N6, p. 5).

In this extract, the nurse describes a decision making process in which a team approach is employed, where the nurse is a member of a decision making team; but exactly how much the nurse is involved within that team meeting remains open to conjecture. However, one thing is relatively clear: whilst none of the interviewed nurses suggested that they ever lead any debate between parents and the medical team concerning the decisions of the parents to accept or refuse a particular treatment regime, there was evidence (as above) that they did instigate debates between physicians and parents in the face of potential problems. Furthermore, there are instances where nurses believe that they are able to contribute to the discussion, and seek to do so rather than await an invitation from a physician. As the following nurse maintained, in the case of *withdrawal* of medical treatment (as occurred in, for instance, the Baby L case), nurses perceive their role an integral one along side other health professionals:

I don't think you've got a new breed of nurses who are in any way more objective or outspoken, but I do think you've a breed of nurses now who are a lot more thoughtful and a lot more aware of their role or our role in the whole situation. Nurses who are a lot less willing not to take a part; I mean we're involved in every, I can't think of one situation where the care has been withdrawn and the nurses haven't been involved, because there's much more of a sharing with that particular burden (N1, p.8).

Ideas about new professionalism are indicated in this nurse's narrative (i.e. 'a breed of nurses now' who are 'a lot less willing not to take part', and who 'share a particular burden'). This relates to the different temporal domains of medicine and nursing. As previously discussed in Chapter Seven, medicine, which has a future focussed domain, is therefore orientated towards the possibility of cure; nursing, which has a present time domain, is orientated towards care. When cure is seen as no longer possible, nursing will always seek to continue to address the present demands of care that is associated with the nursing domain, and take over. If, for instance, a child no longer fits a cure orientated clinical picture, then the nurse may emerge from an in-between position and 'claim' the family as part of her/his domain based on caring. This occurred in a significant way in the Baby L case, where nurses closely attended to the parents and child at home and even went to the funeral of the child. It is clear that the nurse perceives a significant difference between nursing involvement in the care of a child who will eventually die after treatment has been withdrawn and nursing involvement in planned medical interventions for a child who may respond to treatment. The nurse understands that when cure is no longer a possibility and active treatment is withdrawn, the child enters her domain of

responsibility,¹⁶⁰ and therefore the nurse considers that she has more to contribute by means of (shared) expert care, and fully expects to do so.

The nurse as the patient's/parents' advocate

The nurse may attempt to ascertain the parents' position on possible medical treatment and their level of anxiety (Hallström & Elander, 2005) by easing the parents' path for them before or just after an interview with a physician has occurred. This role is akin to that described by Bishop and Scudder (1996) as the nurse's fostering of the patient's (or, in paediatric nursing, the entire family's) well-being. Note how the following extract from a nurse's interview tends to mirror Mary's narrative (see Chapter Six) about what happened to her and her child around the time of their admission to hospital:

They've been to the GP's, present to hospital, and suddenly they're told that this, this, and this needs to be done. And I think they have struggled to get anybody to listen to them and now someone has suddenly taken control and they feel like they have no control. And I have found that there are families like that; that if you communicate and you take everything like every step of the way... I just make it really a priority that I explain everything as I'm going and even to the point of because I've worked in paediatrics so long knowing what the doctors are probably going to want to do. I mean so to the point of saying well this is likely to happen and given several scenarios of what may happen so that they think about how you know whether they're going, what's going to be done and whether they're going to agree to be doing it (N5, p.2).

As a member of the health care team who sympathises and assesses parental demeanour in a comprehensive or holistic fashion, some nurses will attempt to become a 'companion', or a 'partner' or even a 'good friend' for parents – even those parents who seem discontented and 'troublesome' (Noddings, 1984). Such positioning reflects a level of understanding that is born out of everyday practical experience and observation:

I think you have to have an enormous respect for those parents [i.e. resisting ones]. To be honest with you that is the trouble. The child just cannot exist in isolation. And one of the biggest mistakes I think we make is ...that what we're looking after the child in isolation. [Yet] he really can't exist without mum and dad or a family or foster parent or whoever has to check in for that child ... I do really find that, we need to ...have much more of a sense of how the family feel (N1, pp5-6).

This nurse emphasises the relational aspects of nursing work (the child does not exist in isolation). Sets of expectations about nursing care within society combined with their position in both the everyday care of patients enables nurses to offer a more familiar and warm relationship to the parents of a child than doctors because, as generally argued by Benner (1984); Benner & Wrubel (1989) and other contemporary nurse commentators, nurses *are* personal and/or

¹⁶⁰ What is nursing's domain of responsibility? According to the International Council of Nurses (2000), "Nurses have a fundamental responsibility to promote health, to prevent illness, to restore health and to alleviate suffering. Their primary responsibility is to those people who require nursing care."

intimate, both objectively *and* subjectively connected to the lives of those for which they care, and hence professional care ‘experts’ within their own right. Nurses identify with, and claim the role of patient (or parent) advocacy, which draws upon human rights arguments or moral appeals towards fairness (Johnstone, 2004).¹⁶¹ In pursuit of the closer identification or positioning of a nurse to the parents needs and rights through nursing advocacy, the nurse interviewee in the following extract offers her view about parents’ right to choose in regard to their own child’s treatment:

I think everyone’s entitled to choose. When a family decides it’s like a religion isn’t it really? ...When they decide that they’re doing the very best that they think for their child, they honestly believe that they’re doing the very best for their child. Well then, I think they’ve got every right to (N3, p.9).

In this extract, the nurse draws upon a neo-liberalist discourse of individual rights and a medical discourse about consent and choice in order to support the parents’ viewpoint about their right to decide. Even though parental rights are clearly laid out in both medical and legal documents (see Chapter Three), there remains a problem within nursing about how to respond to resisting parents when the nurse herself appreciates and (covertly) supports that resistance:

It is really difficult. And I’ve nursed in areas where...you know, the outcomes, they are really, really... if the chemotherapy doesn’t kill them, you know, then usually the tumour does ...Having the knowledge that I have I, I don’t know if I would. I think they [talking of the Williams-Holloway parents] made the right decision. I think they gave him quality of life in the time he wasn’t having treatment and if they hadn’t done that and they’d gone ahead with treatment he would have spent some pretty miserable weeks or months with complications from the chemotherapy (N5, p. 8).

This nurse is able to express empathy for resisting parents such as the Williams-Holloways, albeit sometimes privately, because of her familiarity with both the technical and objective side of medical treatment as well as the more intimate and subjective side as well.

If parents are perceived as being ‘off-side’ and in need of a calming, friendly face in the dramatically different field of the hospital that they now find themselves within, the nurse may not only assess the parents’ level of resistance, but also seek ways to alleviate that resistance. In the following narrative, the nurse achieves this through personal and subjectively orientated means:

...I’ve usually got them on side anyway; if I get them a cup-o-tea - ha, ha, ha! Relating something in common with them maybe, and talking about their child, asking about the family, you know, sort of getting a rapport - just for the sake of it. If you’re talking about a treatment that the child might need, sort of once again it’s sort of educating on an equal basis type of where they’re at, where the family might be at, whether they understand what this is about, give them a little bit of background maybe about the disease or whatever their child has got. I mean that’s not going to be every patient of course, but with the more chronic patient it certainly would be. You’d be certain to

¹⁶¹ Nursing advocacy has long been recognised in nursing codes of ethics; such as for instance, the International Council of Nurses Code of Ethics (2000), or the New Zealand Nurses Organisation’s Code of Ethics (2001).

make sure they understand. Always, never, I don't think I've ever left the room without saying "is there anything you want to ask?" or "I'll be back in a while if you think of something you know let me know..." (N3, p.13).

This nurse presents herself as an equal to the parents and by creating the space for everyday conversation to occur prepares the ground for the physicians. Nursing work involves constantly liaising between and between parents and physicians within the confines and protocols of the health care facility. This role, and the concurrent roles of preparing/smoothing the ground for, and acting as a go-between for parents and physicians (Bishop & Scudder, 1996), is therefore one where constant attention is needed towards balance and coordination.

The nurse as an expert 'go-between'

The notion of the role of a nurse as a skilled 'go-between' is a common feature of research that examines health care 'microsystems'¹⁶² and the key roles of various members of the health care team (Johnston & Smith, 2006; Krogstad, Hofoss, Veenstra & Hjortdahl, 2006). The nurse's role is now seen in terms of discourses about 'new-professionalism', as nurses find themselves operating within complex and technically intense health care systems. For instance:

Nurses seem to be concerned about the vertical as well as horizontal organizational coherence in their work, which may reflect the multidimensionality of nurses' work. Because nurses have a coordinating role, the responsibility for shuttling between professional, organizational and relational tasks makes them utterly aware of organizational gaps and inconsistencies. Nurses inhabit an organizational position from which they overlook the local system's impact on professional competence as well as cooperation and workflow (Krogstad et al., 2006).

In this more recent examination of the professional nurse's 'go-between' role, the nurse is now perceived to be an expert 'co-ordinator', working across and between several dimensions to fulfil their many tasks and responsibilities. This reappraisal of the nurse's role is perhaps a more accurate description of modern nursing practices, and indicative of the significant skilfulness that nurses exhibit in modern (paediatric) practices (Hockenberry, 2004). In this regard, nurses no longer consider their role as an entirely supportive and secondary one to medicine, but they do continue to work in institutions where hegemonic disagreements (based on 'old professionalism-new professionalism' distinctions) between the nursing and the medical professions still affect their practices (Varcoe et al., 2004).

Nurses' opinions about parental resistance did not fully concur with the opinions of their colleagues in the medical profession, but neither did they stand in contrast to them *in the medical field*. A tension therefore emerged as nurses demonstrated an ability to understand the (resisting) parents' perspectives, and at the same time chose not to resist the doctor's wishes.

¹⁶² Microsystems in health service are small teams working together on a regular basis to serve the needs of a discrete sub-population of patients. In this definition, microsystems include patients, clinicians, processes and recurring patterns (Nelson, Batalden, Huber, Mohr, Godfrey, Headrick et al., 2002).

That is, they felt sympathy for the parents, but did not necessarily support their decisions in a more public fashion, especially with the attending physicians. At the same time, some nurses do find ways to support parents in their decisions, and some of the interviewed doctors showed an understanding that nurses felt obliged to support parents, or at least show an awareness of the parents' viewpoint. In short, the nurses interviewed for this study illustrated their sometimes invidious 'in-between' position in the health care hierarchy as one that limits their involvement in medical decisions, but enhances their involvement in care decisions where parents were as much a part of that care as their children. In this role, the potential for nurses to maintain a position of public and personal trust through their work in more intimate aspects of care (Chambliss, 1996), to represent a 'human face' in a world of advanced medical technologies and specialised procedures (Woods, 1997) and to fulfil their established role as advocates for their patients or parents remains entirely viable.

Summary

This chapter has presented an analysis of parental resistance from the perspective of the nurses interviewed for this thesis. It has been maintained that nurses are positioned in an in-between role in their work with seriously ill children and their parents, and in their relationships with medical staff and hospital managers. This positioning has been attributed to the nurses' historically acquired field and habitus, the subordination of their profession, and more recently, nursing's attempts to reposition itself through the discourse of 'old professionalism-new professionalism'.

Within these constantly shifting positions that occupy the 'middle ground', nurses attempt to respond to parental resistance in ways that reflect both an understanding of the requirements of medicine, and also of their own professional standards. For instance, the interviewed nurses share generally similar views on the causes of parental resistance to those offered by the interviewed doctors (religious beliefs, psychological factors, and cultural differences), but they differ in their approach and management of parental resistance. For these nurses, parental resistance is a problem that drives them to collaborate with members of the medical profession to influence parents' decisions if necessary, but they will also attempt to find ways to support parents using their advocacy skills if necessary. Nurses will also work as team members within the ward or unit, but at the same time practice in a fashion that clearly illustrates their considerable pragmatic skills as expert 'go-betweens'.

It is tempting to therefore conclude that nurses are either the 'glue' that may hold the means of effective communication, cooperation and compliance between medical staff and parents; but it must be recognised that at the same time, nurses may also be a cause or at least an exacerbating influence of the seeds of parental resistance in their own right (as noted in Chapter Six). To conclude, for resistive parents, and for the doctors that they work alongside, nurses are ideally placed to offer considerable support, but only if allowed to do so within a health care environment that has never fully realised the enormous potential of the nurse's role.

CHAPTER NINE

Parental resistance revisited: 'mobile and transitory points of resistance'

Foucault is also clear that, although great radical ruptures or revolutions have taken place, and although rigid general divisions (usually in a binary form) do exist, what is much more important are 'mobile and transitory points of resistance' which are constantly shifting the focus which these social cleavages are understood. It is the mundane or everyday acts of resistance that potentially produces profound effects (McHoul & Grace, 1993, pp.85-86)

Introduction

This chapter reviews the main findings of the study and recaps some of the central arguments that developed from those findings. A discussion of the complexities of parental resistance in relation to the various discourses created around it serves as an overview of the main theoretical and contextual ideas within the thesis. This is followed by an examination of the converging and competing discourses of parental resistance in a final comparative outline. The potential of parental resistance which is to be read as the deployment of alternative knowledges is a central theme in this discussion. As this thesis emerges from within an applied discipline, an overview of some of the possible strategies for enhancing parent-clinical staff relationships and decision making processes is offered via some thoughts and suggestions on practice issues. The chapter ends with a brief consideration of the implications of the study for nursing education and practice, its limitations, and suggestions for future research.

Parental resistance – a complex issue

To illustrate the discursive elements of parental resistance, this research initially examined known national and international cases of resistance taken from media and law reports. These examples were termed as cases of *radical parental resistance* (Chapter One), indicating fundamental parental opposition to medical wishes that led to radical actions and consequences involving resistance to medical treatment and/or the law. Recognisable features of these cases included a preliminary period where parents and medical authorities met together over a serious health situation involving a seriously ill child; the emergence of *profound* differences of opinion between health care staff and parents over the proposed treatment for the child; the consideration and eventual use of legal means by physicians (such as searches by the police, summons, court cases, the imposition of penalties or sentences) in an attempt to force a conclusion to an apparent impasse; and in nearly all cases, prolonged media attention, either as the case emerged from preliminary legal proceedings, or as the case became known to the media after the event.

An examination of the literature related to parental resistance (Chapter Three), identified that most of the talk on the issue was provided by a range of commentators and experts, whilst parents were largely silenced. For instance, the literature represents the rational and objective medical and legal ideas relating to parental consent and decision making, but rarely offers alternative viewpoints from parent perspectives. In this regard, tensions between the medical and legal interpretations and representations of individual (and objective) choice and the relational (and subjective) choices of parents and their children are sometimes difficult ones because the perceived options available and goals may be different. Parents resistance speaks to the illusory aspects of individual choice within a health care system that is largely designed to reflect the overall desires of the state through the central regulatory and surveillance mechanisms that are medicine and law in the guise of meeting the needs of society at large.

Media discourses on parental resistance (Chapter Four) suggest that the media provide clearly identifiable themes and human archetypes that are embedded, either covertly or overtly, within their discursive fields of operation. Overall, resisting parents were represented as mainly negative characters that sit outside the symbolic 'mainstream' and challenge the maintenance of mainstream values. For instance, resisting parents are variously constructed as 'culturally different', and/or 'misguided or misinformed', and/or as 'ignorant or malicious'. On the other hand, physicians are usually presented as 'proper' representatives of medical treatment while alternative health practitioners are presented mainly as 'quacks'. Children are nearly always suffering innocents 'fighting the disease' and both they and their supportive parents are 'heroic'; parents who resist, however, are noted as unheroic and in those terms noted above. An examination of media texts also indicated that the law acts as the state sanctioned arbiter of societal behaviour, and that the media themselves sometimes takes on the mantle as critics and conscience of society. Experts from medicine and the law prevail in providing media commentaries that usually condemn parental behaviour in either a condescending or a condemnatory fashion. The media's role of re-presenting socio-cultural and ideological perspectives on parental responsibility in relation to medical advice regarding the treatment of a seriously ill child is therefore unmistakable. The media acts as a major force in the formulation, distribution and direction of public discourses through the *selective* use of speakers, images and language. Subsequently, it is maintained that because media discourses are predominantly performed within the public arena, they also influence and shape the construction of social reality.

The law frames and sometimes intervenes in cases of health care decision making, especially when medical representatives confront the issue of parental resistance by using legal means to enforce recommendations for medical intervention (Chapter Five). By delineating unacceptable behaviours, legal precedents implicitly set the expected norms and behaviours for all parents against which cases of parental resistance are judged. The interests of physicians and

health care institutions are nearly always prioritised over the wishes of parents and their families. In this fashion, the state's representatives (medical and legal personnel) bring forces to bear on resisting parents in a combined and concerted fashion. When the law becomes involved in resolving or prosecuting (radical) cases of parental resistance to medical advice, a contradictory 'body politic' emerges based upon the tensions between the individual rights of parents and children and the collective regulation of those rights. The child is part of a socially recognised collective linked together by strong bonds of familial purpose, but at the same time the child is also perceived as an individual by the state, and therefore entitled to the same individually orientated rights under law as anyone else. Should it be (legally) perceived that their right to life or to medical treatment is being denied by their parents, then parents may face the normalising judgements of the law in court proceedings. Yet, criminal prosecutions and proceedings themselves are based upon judgements that are subject to interpretation and indeterminacy leading to contradictory outcomes among the five media cases discussed in this thesis. As such, parents may face a series of relational and legal dilemmas if their interpretation of what may be in their child's best interests clashes with the interpretation of the state via legal and medical representation.

Slowly emerging and experiential forms of parental resistance are formidable and powerful; once established, they may not dissipate easily. Resistance may be a permanent feature for Mary and for other parents who have encountered similar discursive elements in their relationships with members of the medical profession. It is also likely that if the same parents ever have to use medical facilities in the future, a type of pre-existing resistance will already be present. But what of the parents of Baby L, Liam Williams-Holloway, Calcb Moorhead, Tovia Laufau and Caleb Tribble, who appeared to resist the medical system almost from the start? Their resistance was not considered to be a gradual and reluctant event that was slowly formed through interactions between parents and medical staff within the system over a period of time. Their resistance was termed 'radical' because they resisted medical intervention almost right from the start and ended up in Court. In the case of Baby L, the parents were in fundamental opposition to the *withdrawal* of medical treatment, and went to Court to maintain that treatment. That the parents lost this attempt and their child died was therefore not a consequence of parental resistance, but of medical resistance to treatment (which further suggests that resistance is a 'mobile and transitory' element in *all* relationships). In the second case, the Williams-Holloways, the parents agreed to medical treatment for a period of time but when the effects of the treatment became known to them, sought to have their child treated by alternative means. That their case went to court, but was later abandoned, and that they attracted considerable public support, speaks of the convoluted and controversial nature of their situation. In the Laufau case, the parents did everything that was expected of them at the start, and only acted as they did because their own child, who was thirteen years of age at the time, had demanded that

he had the right not to be treated. The Tribble parents never fully rejected medical advice, and allowed visits from the nurse on a number of occasions. That they did not understand the seriousness of their child's situation became obvious later at the trial. The Moorhead case is perhaps *the* only case to completely exhibit all of the radical elements noted at the start of the research. The parents were reluctant to seek medical advice in the first instance, and when they did so, they rejected this advice and fled from the hospital with their ailing infant. They ended up in Court and were the only parents of the five cases to go to jail for their actions.

The above arguments were compared with material taken from the parents, doctors and nurses' interviews, where several instances of parental resistance were explored. They ranged from minor disagreements between parents and clinical staff to major disruptions where the relationship between parents and clinical staff disintegrated over time leading to inevitable resistance. None of these cases attracted media attention because they had never become subject to the legal, and therefore the public gaze, in the first place. Subsequently, it is argued that an examination of 'everyday cases' of parental resistance through attention to choice, consent and decision making in health care settings suggests that there is a cleavage between the experiences and conceptual representations of parents and the professional practices of doctors and nurses (and the literature that relates to those experiences). This gulf is characterised by parents in ways that are different from how that they are represented by doctors, and by the hegemony of biomedicine, which places expectations on parents to conform (Bourdieu, 1984) and respond within expected norms (Lupton, 1994a). However, when examining the doctors' views of how they seek to respond to parental resistance, certain discursive elements began to diverge from those found in the parents and nurses' interviews.

Doctors concentrated their responses on maintaining the doctor-parent relationship by claiming that it was they - and not particularly anyone else - that dealt with resisting parents (Chapter Seven). They did so by improving communication and changing the language to suit the parents, often representing the problem of parental resistance as a need for them to be clearer in intent and repeating the message as necessary until a resolution is found. If this strategy was unsuccessful, then negotiation and compromise was also attempted until such a time as when it was decided that a more direct and therefore paternalistic approach was required. Doctors allowed harmless alternative therapies, and/or got more support from other doctors and/or modified their own sets of understandings about 'normal' treatments to allow (harmless) alternative treatments to run along side their own. As a last resort, doctors would take the case to the law, which they saw as a useful ally. Hence, the talk of physicians suggest that they share a reasonably widespread belief that parental resistance occurs in situations where the medical perspective has not been communicated satisfactorily; the 'solution' being found in better ways of communicating. However, as the material representing the parents' perspectives clearly showed, this response that fails to show adequate appreciation of the many 'tipping

points' within the institution that may affect parental decision making and acceptance of medical treatment.

Nurses, on the other hand, rarely presumed that they were responsible for dealing with resisting parents in any fashion where they had to lead the response (Chapter Eight). On the contrary, the interviewed nurses spoke frequently of their 'in-between' status, being caught between what was termed ways of behaving under 'old professionalism' and 'new professionalism'. That is, between supporting hierarchical relationships and being more interactive between those relationships; or supporting the absolute right of doctors to impart their knowledge and decision making in sometimes paternalistic ways versus an emphasis on interpersonal and partnership skills, or even being somewhere between 'value free' or 'value laden' in their dealings with parents. Nevertheless, nurses exhibited a more personalised account of their experiences than doctors, and their narratives tended towards a professional discourse on parental resistance that concentrated around an examination of their own circumstances as 'in-between' health care professionals as much as it did about their relationships with parents. In this may be seen the current professional situation of nurses within a nutshell, being frequently 'caught' in between their responsibilities towards, and advocacy for parents and their ill children, and doctors who insist on maintaining the lead role in responding to parental resistance.

Overall, the interviewed nurses indicated that they positioned themselves as 'team players', always ready to contribute, being a supportive (of both parents *and* physicians) bystander and sometimes the expert 'go-between' whilst the doctors 'got on with the job'. The expert go-between was a different way of responding to parents who resisted medical advice than the doctors. For instance, the nurses presented themselves in the main as both parents' supporters *and* medical collaborators, literally as being in-between parents, physicians and the institute. Such a role was therefore problematic, because those nurses who attempted to support both parties in the dispute could potentially become the servants of both but valued (as mediators) by neither.

Parental discourses within the overarching field of health care, and in particular on the discursive fields of physician-parent and nurse-parent relationship offer significantly different insights into the nature of parental resistance (Chapter Six). The interviewed parents provide narratives concerning their reality in coping, accepting and/or resisting during what for them was a major crisis. For instance, in an examination of the main changes that occur as a parent faces the unfolding situation of her child's sudden illness and gradual decline, Mary's story is both powerful and illuminating. When framed within Young et al's (2002) descriptions, such as 'becoming a parent of a child with cancer', 'adjusting to the situation', 'settling into a different role', 'living with the threat' and 'resigning to fate' the full impact of Mary's situation is identified. When other parents' stories are considered, it became clear that it is within the new

and often frightening world of institutionalised health care that parents seek to maintain their roles and identities. To do so, they have to cope with the impact of the medical 'field' and all that it presents. This includes the discursive elements of power games that affected parental relationships with the medical team, including the language of medicine and symbolic violence, trust between parents and medical staff, the effects of medical habitus, challenges to the parental role and identity. Those parents that are able to adapt and cope with such challenges (such as Ann) do not show the same responses as those parents who find it more difficult. It is when these discourses and practices are either singly or collectively resisted that parents such as Mary, Rose (and to a lesser extent, Stephen) and Yvonne, then take up the mantle of a resisting parent. What drives such parents to resist medical advice or proposed treatments is not then ignorance or malice, or the machinations of their own religious or cultural belief systems, but factors such as loss of faith in clinical staff, or loss of trust that they can perform their caring work in a fashion that reflects the parent's view of caring; or loss of hope that the system can respond in appropriate ways, and even despair at the absence of perceived altruism amongst the medical staff. It is under these conditions that some parents will inevitably resist representatives and/or their practices within the health care system.

Hence, the emergence of parental resistance, if and when it appears, is framed within a Foucaultian 'antagonism of strategies' such as 'using the system' and 'playing the part', 'standing ground', 'taking back control' and 'maintaining control'. These discourses differ from those of the media, medicine or nursing which tends to concentrate on isolated factors which enable an insufficient explanation of the complexities of parental behaviour and professional responses. Overall, the parents' interviews suggest that resistance involves several discursive elements, such as medical habitus and field, symbolic capital and violence, and challenges for parents concerning both their perceived roles and identities within the medical system. It was also demonstrated that, for some parents, these elements created an atmosphere of unease and anxiety that may then be 'tipped' or further exacerbated by any incident within the medical environment that damages the parents' faith, trust, or hope within the medical system. Should this occur, then it is argued, the likelihood of some level of parental resistance are greatly increased.

Parental resistance – converging and competing discourses

Foucault (1979) elucidated his thoughts on power and resistance by claiming: "Where there is power, there is resistance, and yet, or rather consequently, this resistance is never in a position of exteriority in relation to power" (p. 95). In the case of parental resistance, it has been argued in this thesis that there is an ever present potential for conflicts of will and desire between parents and clinical staff. This potential exists within the multiplicity of relationships between parents and health care providers. It exists within circumstances where there is no particular

external force that imposes its will on parents, but within a field marked by 'differentiations' characterised by medical expressions of social capital that are articulated as status or privilege (Bourdieu, 1984, 1992). Subsequently, the parents of critically ill children find themselves constantly judged and held accountable by standards and protocols that are framed by medical-technological knowledge that operates as a collective power base within society. Parents of seriously ill children face the medical imposition of will within a system that is both alienating and often alarming to them, where they become socialised into a different culture by largely suppressing their own subjectivity for the 'necessary' objectivity of the field (Bourdieu, 1984). Yet at the same time, many parents attempt to respond to such pressures in a variety of ways, some of which are passive, and some which are either covertly or overtly resistive. In their 'conflict over competence and status' (Bourdieu, 1987b), parents therefore face considerable degrees of legitimised symbolic violence (Bourdieu, 1991) within a power-resistance nexus. Within this conflict, as Bourdieu maintains, some actors (i.e. physicians) tend to dominate the field, but as they do so, "they must always contend with the resistance, the claims, the contention, political or otherwise, of the dominated' (Bourdieu & Wacquant 1992, p.102).

Parents are individuals with interests that are socially and legally defined prior to their reconstruction through their relationships with medical power. These interests, such as may be seen in their relationship, responsibilities and intimate knowledge of their child, are not easily put aside by most parents; their responses illustrating the more unstable aspects of the new relationship that they have with clinical staff crafted out of necessity rather than choice. That there are parents who take their responses to more radical extremes is therefore not a question of a few isolated cases, but indicative of one section of a whole spectrum of resistive possibilities. Subsequently, there is an ever present resistive force in parents, ready to respond to any attempts from *any* external sources to control the destiny of their children beyond acceptable levels. Rather than being an exception to patient-physician interactions, narratives of parents who resist treatment for their seriously ill children are able to illuminate the complex association between parents and medical conventions. It is therefore possible to see parents who resist not as peripheral to the medical encounter but as examples of how patient-physician relationships become codified, constructed and crafted through the everyday practices of individuals, the institutional routines of the hospital, and in state regulations relating to choice, informed consent and the respective responsibilities of parents, physicians and nurses.

Thus, it may be argued, parental resistance is an ever present discourse that permeates *all* physician-parent relationships. It may be over-dramatised in the public gaze by the media and take on added public attention when a case goes to trial, but it is more likely to arise from small incidents that may seem innocuous from a medical or nursing perspective, but are highly significant from a parental perspective. Yet, the difference between the largely objective opinions of medical and nursing staff as to the causes of and suitable responses to parental

resistance, and the experiential and highly subjective opinions of parents has been illuminated in this thesis. Parental resistance is ever present; it is a response to the power base that is medicine within the discursive field that is health care; it is inevitable.

Strategies for clinical staff in responding to parental resistance

It is suggested throughout several sections of this thesis that ‘fighting and/or litigating’ parents because they are being resistive to medical advice is an action that will only serve to further alienate some parents, and punish them for actions that they would otherwise regard as normal. For instance, parents may be expected to protect their own children from perceived harm, from whatever source; to be afraid for one’s child’s welfare, and/or to seek out alternatives when conventional medical treatments appear to offer limited possibilities. Hence, litigation should be one of the absolute last resort, and not held over parents as a possible outcome should they fail to concur with medical advice.

It is also suggested in this thesis that the options of compromising, negotiating and similar conflict resolution methods used by doctors, and sometimes other clinical staff, remain a viable possibility. Nevertheless, it is no easy task to achieve a situation of mutual integrity through compromise, let alone a negotiated resolution with frightened, or angry and/or distrusting parents. As the Paediatric Society of New Zealand (2001) note in their attempts to map out guidelines to alleviate the problems associated with parental disagreements and conflicts with doctors, there remains the possibility of mistakes. For instance, they note that ‘best interests’ argument may be used ‘manipulatively and coercively’ and that individual and cultural nuances often make a difference but may be easily missed or put aside. Thus, compromise focussed approaches will remain difficult for some parents, who may perceive that their values and beliefs are not being given sufficient attention, and for some doctors and/or nurses, who still perceive their role as one involving the exercise of varying degrees of clinical surveillance and control. If compromise in the clinical setting is to be of any real value, then steps should be taken to neutralise medical hegemony, promote the parents’ and/or the child’s opinion (through an independent trained advocate if necessary), and, before all else is attempted, gather as much information about the parents’ values and preferences as is possible. It is clear from this research that such things as religious beliefs and cultural practices may be not the stuff of ‘a brief mention in the notes’ but potentially crucial information for immediate and later use.

There are a number of suggestions concerning possible strategies for either disarming growing parental resistance, or at least minimising its effects. In this task, it would be wise to carefully heed the messages within the narratives of parents. Where there is trust, which is based on openness, and a greater understanding of the impact on parents and their children of the medical field, there may be an increased possibility that parents will feel less agitated to resist medical advice. However, to achieve this, clinical staff should abandon some of the practices

that can disturb some parents so much, such as the playing of power games, the use of difficult language and symbolic violence. Such factors cause unnecessary distress and anxiety for parents who are already highly vulnerable, uncertain and uneasy. When parents lose faith in the health care system, trust may also fade, and if that is diminished, then loss of hope may also follow. As an example of a possible change to existing practices, and because good communication is so important (as the interviewed doctors and nurses maintained) the methods of communication between clinical staff and parents need to be reviewed and revised. In 2002, at a conference attended by paediatric physicians and nurses, I offered a preliminary list of suggestions in regard to improving parent-staff communications (Woods, 2002). On re-examination at the end of the thesis, these suggestions (now slightly modified) are still relevant. Briefly, the suggestions are:

(a) 'Seek a shared goal', where an emphasis should be placed upon mutually supporting the same *goal* or predicted outcome of intended interventions or treatments in life threatening situations. This is crucial because the parents may not necessarily share the same goal as the doctor, either initially or later on. The expected result of the proposed treatment may have to be re-defined; this and all other discussions between doctors and parents needs to be *in depth* in matters of crucial treatment decisions involving a seriously ill child.

(b) 'Communicating in depth' involves greater attention to situational, relational and narrative factors that may enhance the abilities of parents and their child to engage in ways that open up spaces for discussion rather than close them down, to increase their understanding of the situation, and relate how it affects them in meaningful ways. This requires the development of open, subjective and *relational* discourses that transcend medical objectivism. Most importantly, medical or nursing mistakes should never be covered up when dealing with the parents of a seriously ill child; honest dialogue is crucial.

(c) 'Carefully negotiating throughout the crucial process of the preliminary diagnosis' *before* the 'best treatment' option is even suggested. Unless the parents' views on appropriate responses to their child's illness are ascertained - especially their beliefs and values - in the early stages of contact between the medical team and the parents, other important decisions may be derailed from the start;

(d) 'Reconsidering the decision making process' where the lingering use of the methods of traditional medical decision making (that are based largely around the application of a rational approach that leads to 'either/or' decisions) is confrontational, authoritarian, and coercive. The use of contemporary approaches to decision making, in conjunction with challenges to the abstract and generally 'uninvolved' nature of traditional medical responsiveness, may be of benefit. If necessary, there should be formal procedures in place to intervene as necessary.

(e) In difficult and seemingly deadlocked disputes between parents and doctors, the use of third-party mediators (such as nurses, who are members of an 'in-between' profession) could

lead to a more balanced process of decision making (Woods, 2001). For this possibility to occur, health care professional relationships may require a rethink. The most likely places for such a rethink are in healthcare education, and in institutional practices and policies.

Implications for education and practice

Roberts and Sarangi (2003) offer an analytical distinction between three modes of interrelated talk (professional, institutional and personal experience) in relation to the degree that practitioner-professionals 'take up' discourse-based research in practical or policy issues. They describe personal experience discourse as "talk concerned with the individual's experiences and feelings" (p.343); professional discourse as "the talk of doctors in practice, in doctor-patient interviews, in case rounds, in hospitals, and in a range of doctor-doctor discussions and meetings" (p.343); institutional discourse is represented by "the ways in which they [GPs] account for this talk" in everyday competencies and practices presented in institutional terms. Their distinctions of uptake of discourse research are now used in this brief discussion to characterise the implications of this research for education and practice.

In personal experience discourse, the talk of this thesis offers insights into the intimate world of parents in crisis that otherwise may be misinformed, misrepresented or misunderstood in medical and related literature, media reporting (and even legal responses). As such, the narratives of the five parents who were interviewed for this research offer insights into the world of every parent who, through circumstance, is forced to adjust and respond to an alarming situation not through choice, but through necessity. Such insights are a potentially useful key to a better understanding of the personal experiences of parents in the more 'radical' cases of parental resistance; that is, whether parental resistance begins at the first medical consultation or not, or develops over time, there are factors that are common to both. Trust, confidence, time to adjust to new circumstances, allowances for differing cultural and/or religious preferences and a range of other experiential elements, are all important in an understanding of the parents' personal experiences in critical situations involving their child.

In an examination of mainly professional discourses involving the talk of doctors and nurses in practice, the talk has been generally restricted to professional rather than personal responsiveness towards resistive parents (even if, as Roberts and Sarangi [2003] maintain there is always a degree of 'slippage' across the modes). Therefore, as the interviewed doctors and nurses' narratives suggested, their perspectives were professionally inspired responses that failed to appreciate the full impact of the institutional field and their own habitus on parents and their children. It therefore is of considerable importance that neophyte (and established?) paediatric physicians are educated in ways that examine the effects of hospitals on parents and children (Darbyshire, 1994), the 'tipping points' of parental resistance, and in the nuances of health care decision-making overall. These adjustments should help members of the medical

profession to avoid as far as possible either the more commonly experienced and localised disagreements with parents of seriously ill children, and hopefully, the radical cases of parental resistance that have the capacity to seriously affect not only their professional and institutional activities, but potentially their personal experiences as well. Nurses talk has indicated (which was sometimes supported or contradicted by parents talk) that there is much that nurses could contribute when working with parents of seriously ill children, irrespective of the perceived tensions between nurses' capabilities and the often difficult contexts that they work in. Therefore, whilst it may be impossible within nursing education and practice to challenge the power-knowledge base that doctors possess, there may be ways in which nursing students may be better prepared for those inevitable situations where their loyalties are divided, and their involvement of value. For instance, it has been suggested (Woods, 2001), that in such circumstances, nurses could be ideal mediators; but to do so, nursing education would have to be adjusted accordingly, to emphasise and offer an improved knowledge base within the areas of professional responsibility, ethics, and advocacy. Similarly, nurses already in practice may benefit from the knowledge that their role, far from being that of a 'passive-bystander', can be usefully moderating; that is, their very 'in-betweenness' in health care delivery systems may be to their overall advantage, *and* to the specific benefit of child patients and their parents.

In institutional discourse, the talk concerning parental resistance is accounted for in everyday practices that reflect a status quo that eventually must be challenged if new cases of radical parental resistance, and the more commonly experienced everyday cases of parental resistance are to be avoided. In an examination of the institutionalised practices of health care personnel, the various players may wish to consider whether or not their efforts to respond effectively to the intermittent incidents of (radical *and* everyday) parental resistance is as effective as it could be. If, as maintained in this thesis, such incidents continue to haunt medical and nursing staff, often as *personal* experiences that cause them considerable distress, then it is perhaps pertinent that alternative strategies were considered.

Equally important, is that this thesis may serve as a catalyst for a wider and more inclusive debate about parental resistance amongst members of the media, the law, and society at large. This thesis allows for a range of alternative perspectives within these debates and offers an analysis of those discourses. In this, it may be argued that although there are no definitive answers to parents who resist medical treatment for their children, there are shortcomings and unacknowledged agendas/motivations within media and within state agents such as law, medicine, and to an extent, nursing. These shortcomings are now at least 'out in the open' in this analysis, and may therefore be of use in debates across the social spectrum.

Limitations of the study

In this thesis, discourse analysis was applied to the issue of parental resistance against medical advice and/or treatment. Subsequently, texts from a variety of 'public' and individual (interviews) sources were analysed; the fifteen interview based texts in particular giving the thesis its foundation in the behaviours and practices of individuals. In the use of small numbers, the thesis is not generalisable (i.e. it does not argue for or against the validity and 'truth' of the thesis). Instead, the thesis seeks to highlight the existence of discursive practices within a variety of texts, and to locate them within a social context. Consequently, the thesis involves the application of critical thought to social situations through an examination of overt and/or covert politics within the socially dominant practices of medicine and nursing, as well as all other related discourses within the media or law. The inclusion of parental narratives enhances the analysis, and provides a discursive reality that significantly adds to the overall credibility of the thesis. Nevertheless, because discourse analysis involves essentially interpreting, deconstructing and providing multiple readings of texts, there are issues within such research that may be considered to be 'limitations.'

There are limitations in the selection of the texts gathered for the thesis. For instance, the media texts tended to be based on articles that appeared in one major national newspaper, but other media sources abound and could be examined in equal depth (word limits permitting). Certain media sources, such as television or radio, may even be found to have a greater overall effect on shaping public opinion than newspapers. The legal texts are limited to those that are publicly available and recorded in adequate depth; given more time and available space, more legal texts could have been gathered from legal interviews with lawyers and/or even judges.

Those texts gathered from doctors and nurses were not easily obtained. In both cases, there was considerable reluctance on more than one occasion from these health professionals to commit to an interview, and the 'net' had to be cast wider within the same regional boundaries to attract sufficient interviewees. It is quite likely that interviews with doctors and nurses in another region - where perhaps the previous incidences of radical parental resistance had been less controversial - may have resulted in a different set of narratives and themes. Then again, it would still depend upon the exact nature of the topic and the willingness of clinical staff to dedicate their own time and energies to the interview. It is the parents' texts though that require particular attention.

Parent interviews performed for this thesis were very difficult to obtain, and clearly the narratives of five parents (four main sources plus one partial) is but the tip of the iceberg in terms of representation. It is also highly likely that of those four main interviews, at least three were with parents who had particular points to make and subsequently further interviews with other parents and a more passive topic (such as 'communicating with doctors and nurses' or 'what bothers parents in acute paediatric settings') may yield different possibilities.

Nevertheless, all of these limitations aside, the research remains a discourse analysis that could lead to fundamental changes or revisions of the practices of institutions, health care professions, and society as a whole.

Discourse analysis does not provide tangible answers to any of the problems more usually associated with 'scientific' research, but it does open up access to social problems that persist in modern society; in doing so, it exposes the ontological and epistemological assumptions behind texts that are themselves conditioned and inscribed within a given discourse. That there are many possibilities of analytical interpretation of such discourses will always be a limitation; the reliability and the validity of the research/findings depends on the force and logic of the arguments within the thesis. Yet it is hoped that by exposing and illustrating the discourses that swirl around parental resistance, a contribution will be made to both the insight and knowledge base of those who seek to perform research on this topic in the future.

Suggestions for future research

Cases of radical parental resistance are not a minor or temporary aberration in the general scheme of the medical treatment of seriously ill children. The research has shown that parental resistance is a significant issue that is an ever present and sometimes contentious feature of physician-parent relationships. Furthermore, such resistance should be expected in one form or another within paediatric health care settings rather than seen as an unusual or rare. It has been argued that discourses surrounding parental resistance have been overshadowed by other, more dominant discourses, such as legal and medical discourses, that interlock and support each other in ways that have been quite pervasive and successful.

One aspect of the necessary opening up of future discourse may well rest with the ways in which the media handles cases of parental resistance in the future. To date, parental resistance has been, and still is, fuelled by the popular but potentially derisory binary approaches of the popular media. Much may be gained therefore, from further research into the ways in which media representations of parental discourses are framed and disseminated. Similarly, the use of legal theory, process and regulations that currently underpin legal concepts such as 'best interests' and 'rights' within legal discourse requires further examination in appropriately focussed and interdisciplinary research.

One thing is certain – there is simply not enough research in the discursive field of parent-physician relationships that examines the *parents' perspective* rather than those perspectives of the clinical staff. Of those research items that do present material that is based upon parents' narratives (Darbyshire, 1992, 1994; Nielsen, 2004), very few deal directly with parental resistance. As both interest in alternative or complementary medicine increases in the western world and increasing numbers of parents and older children become aware of their rights under law, it is definitely an area that demands attention in future research.

Conclusion

This thesis analysis deals with the issue of parental resistance in its many forms within a modern health care system. In doing so, the analysis gradually shifts from more extreme or radical forms of parental resistance and the various discourses associated with such forms of resistance in the media, and as interpreted in law, to an examination of the possible origins and developments of parental resistance by examining the discourses of 'ordinary' parents, doctors and nurses. It was guided via Foucault's analysis of the uses of discourse as through the use of his analytical ideas of how 'power-knowledge' is created in our societies and with what purpose or effect; and via Bourdieu's exposition and theory of social distinctions. The 'problem' of parental resistance may be seen from critically alternative viewpoints that should enable those more closely involved – parents, parent support groups, lawyers and judges, journalists and reporters, doctors and nurses - to relate to that problem in different ways. It is hoped that this thesis encourages others to ask different sets of ontological and epistemological questions; acts as a catalyst for potentially beneficial changes that could occur in the practices of the medical and nursing professions when dealing with parents and their seriously ill children, and contributes towards a more inclusive and tolerant society as a whole.

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APPENDIX 1

LETTER OF INTRODUCTION

An investigation into the issues surrounding radical disagreements between medical personnel and parents regarding the proposed medical treatment of seriously ill children.

Request for potential volunteers

My name is Martin Woods and I am currently employed as a lecturer by the School of Health Sciences, Massey University, where I am also enrolled as a PhD student. My research supervisors are Professor Julie Boddy of Massey University, and Professor Megan-Jane Johnstone of the RMIT University, Australia.

I would like to invite you to consider participation in my research project. I seek interviews with doctors, nurses and parents in regard to their views and experiences in situations involving disputed medical decisions concerning the proposed treatment of seriously ill children. I am interested in the general structure of these cases rather than the particular details of each case. A minimum of two years experience in the area of paediatric oncology is required for doctors and nurses, and experience of caring of a seriously ill child (age range 1-11 years preferred) is required for parental involvement.

Your input into the research would be in the form of an interview that would occur at a time between July 2001 and November 2002. The interview would be of approximately 1 to 2 hours duration and arranged at convenient times and venues to suit your requirements.

Please note that patient confidentiality must and will be respected during the interviews. This confidentiality will also be respected in any use of the results in the early stages of the project.

If you wish to consider taking part in this research, or would like to hear more about it, please contact me, either in person or by phone, e-mail or fax at:

School of Health Sciences
Massey University
Private Bag 11 222
Palmerston North
Tel. (06) 350 5799, Ext. 2241
E-mail: M.Woods@massey.ac.nz
Fax: (06) 350 5668

You may also, at any suitable time and for any appropriate reason regarding this research, contact the following supervisor:

Prof. Julie Boddy School of Health Sciences, Massey University
Tel. (06) 350 5799, Ext. 2541

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APPENDIX 2

INFORMATION SHEET

(Doctors and Nurses)

An investigation into the issues surrounding radical disagreements between medical personnel and parents regarding the proposed medical treatment of a seriously ill child.

Thank you for your interest in the proposed research project, which will examine the views and experiences of doctors, nurses, and parents regarding disagreements between medical personnel and parents concerning the proposed medical treatment of children. It should be understood from the onset that I am interested in the *general structure* of these cases rather than the particular details of each case. If you did decide to participate in the research, your input would entail one interview of approximately 1 to 2 hours duration, at a suitable time and venue that will be arranged to occur at some point between June 2001 and June 2002.

Typical questions *for doctors and nurses* may include:

“In your work with seriously ill children and their parents, do you remember any general situations that marked a major change in the overall approach towards decision making of the health care team involving parents and/or their children?”

“Can you recall your input in ways of difficult decision making and negotiating with parents/guardians about proposed treatments for children?”

“In regard to this research, i.e. cases of treatment option disagreements between medical staff and parents/guardians, do you recall any general situations that you either agreed or disagreed with the parents over the proposed treatment of children?”

“What, if any, do you think were the moral or ethical aspects of the general situations that you have described?”

“How would you decide which courses of action would be appropriate in your overall responsiveness to disagreements between medical staff and parents/guardians?”

If selected, you will be invited to ask any further questions you may have about your input in the project, and to sign a Consent Form if you then wish to proceed. An interview will then be arranged with the researcher. The interview will be audiotaped, with your permission, to allow transcription of the data later. The research data gathered from you will be treated with confidentiality. Your name or other identifiable material will not be available to anyone other than the researcher. Every effort will be made by the researcher to maintain your anonymity throughout the research project. Only a pseudonym or a number will refer to each participant.

Furthermore, you will be again reminded that patient confidentiality must and will be respected during the interviews. This confidentiality will also be respected in any use of the results in the early stages of the project. Finally, as an added precaution, the transcriber of the cassette tapes will sign a separate confidentiality agreement before commencing.

If you decide to take part in this research, then you are reminded that:

- a) You have the right to decline to take part or to withdraw from the research at any time.
- b) You have the right at any time during your participation
 - to ask any questions about the research
 - to refuse to answer any question

- to ask that the cassette recorder be turned off
 - to examine any notes taken
 - to read any subsequent transcriptions
 - to terminate the meeting at any time
 - to be informed of the results (on completion of the research).
- c) The proposed research may be of benefit to you, in that it might assist you to reflect on your ethical practice; *or* it may possibly cause you some mental distress if these reflections are of a disturbing nature. If the latter does occur, then measures will be suggested to help you to cope with this distress. ***Under no circumstances*** will your researcher ignore your request for help. If you require support in this regard it will be given, or sought on your behalf with your permission.
- d) Any cassette tapes, notes or other material relating to you will be stored for the duration of the research in a secure place. On completion of the research, the cassette tapes will be returned to you, or, if you desire, will be destroyed. All other materials used in data gathering, such as transcripts or notes, will be stored in a safe place for a period of 5 years for possible auditing purposes and then either returned to you or destroyed.
- e) A summary of the research will be made available to you at the end of the study.
- f) A thesis will be prepared from the completed research, and academic papers, journal articles and conference material based upon this research may follow this.

If you wish to consider taking part in this research, or would like to hear more about it, please contact me in person, by phone, e-mail or fax at:

School of Health Sciences
 Massey University
 Private Bag 11 222
 Palmerston North
 Tel. (06) 350 5799, Ext. 2241
 E-mail: M.Woods@massey.ac.nz
 Fax: (06) 350 5668

You may also, at any suitable time and for any appropriate reason regarding this research, contact the following supervisor:

Dr. Julie Boddy School of Health Sciences, Massey University
 Tel. (06) 350 5799, Ext. 2541

Thank you for your interest in this project and for taking the time to read this information.

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APPENDIX 3

INFORMATION SHEET (Parents or Guardians)

An investigation into the issues surrounding radical disagreements between medical personnel and parents regarding the proposed medical treatment of a seriously ill child.

Thank you for your interest in the proposed research project, which will examine the views and experiences of doctors, nurses, and parents regarding disagreements between medical personnel and parents concerning the proposed medical treatment of children. In your case, your input would entail one interview of approximately 1 to 2 hours duration, at a suitable time and venue that will be arranged at some point between June 2001 and June 2002.

Typical *preliminary* questions *for parents or guardians* may include:

“When your child was seriously ill, do you remember an incident that, in your mind, marked a major turning point in the treatment of your child?”

“Can you recall your input at that point in ways of decision making and negotiating with the medical staff about your child’s proposed treatment?”

“In regard to this research, i.e. cases of treatment disagreements between medical staff and parents/guardians, do you recall any areas that you either agreed or disagreed with the proposed treatment for your child?”

“What, if any, do you think were the moral or ethical aspects of the situation that you have described?”

“How did you decide which course of action would be appropriate in your response to this incident?”

If selected, you will be invited to ask any further questions you may have about your input in the project, and to sign a Consent Form if you then wish to proceed.

An interview will then be arranged with the researcher. The interview will be audio taped, with your permission, to allow transcription of the data at a later time. The research data gathered from you will be treated with confidentiality. Your name or other identifiable material will not be available to anyone other than the researcher. However, as an added precaution, the transcriber of the cassette tapes will sign a separate confidentiality agreement before commencing. Every effort will be made by the researcher to maintain your anonymity throughout the research project. Only a pseudonym or a number will refer to each participant.

If you decide to take part in this research, then you are reminded that:

- a) You have the right to decline to take part or to withdraw from the research at any time.
- b) You have the right at any time during your participation
 - to ask any questions about the research
 - to refuse to answer any question
 - to ask that the cassette recorder be turned off
 - to examine any notes taken

- to read any subsequent transcriptions
 - to terminate the meeting at any time
 - to be informed of the results (on completion of the research).
- c) The proposed research may be of benefit to you, in that it might assist you to reflect on your role as a parent or guardian; *or* it may possibly cause you some mental distress if these reflections are of a disturbing nature. If the latter does occur, then measures will be suggested to help you to cope with this distress. ***Under no circumstances*** will your researcher ignore your request for help. If you require support in this regard it will be given, or sought on your behalf with your permission.
- d) Any cassette tapes, notes or other material relating to you will be stored for the duration of the research in a secure place. On completion of the research, the cassette tapes will be returned to you, or, if you desire, will be destroyed. All other materials used in data gathering, such as transcripts or notes, will be stored in a safe place for a period of 5 years for possible auditing purposes and then either returned to you or destroyed.
- e) A summary of the research will be made available to you at the end of the study.
- f) A thesis will be prepared from the completed research, and academic papers, journal articles and conference material based upon this research may follow this.

If you wish to consider taking part in this research, or would like to hear more about it, please contact me in person or by phone, e-mail or fax at:

School of Health Sciences
Massey University
Private Bag 11 222
Palmerston North
Tel. (06) 350 5799, Ext. 2241
E-mail: M.Woods@massey.ac.nz
Fax: (06) 350 5668

You may also, at any suitable time and for any appropriate reason regarding this research, contact the following supervisor:

Dr. Julie Boddy School of Health Sciences, Massey University
Tel. (06) 350 5799, Ext. 2541

Thank you for your interest in this project and for taking the time to read this information.

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APPENDIX 4

CONSENT FORM

An investigation into the issues surrounding radical disagreements between medical personnel and parents regarding the proposed medical treatment of a seriously ill child.

I have read the Information Sheet and had the details of the study explained to me. My questions have been answered to my satisfaction, and I am aware that I may ask further questions at any time.

I am also aware that I have the right at any time to withdraw from the study and/or to decline to answer any particular question at any time.

I agree to provide information to the researcher on the understanding that my name will not be used within the research, and that the researcher will undertake to take adequate precautions in regard to anonymity when using direct quotations or commentaries within the thesis. For my own part, I will endeavour to maintain the anonymity of those people that may be the focus of my reflections during the interview. These precautions will also be extended to any other named persons or institutes.*

I/we agree/do not agree to the interview being audio taped.

I/we understand that I have the right to ask for the recorder to be turned off at any time during the interview.

I/we agree to the publication of aggregated data after analysis and provided that it does not identify me or my family, or my workplace.

I/we agree to participate in this study under the conditions set out in the information sheet.

Signed.....

.....

Name/s (please print)

.....

Date

N.B. There is the possibility that, in gathering material for the study, certain facts, incidents or recent events may already be known to a wider public audience through media or other channels. In these instances, and although names, dates and other identifying material will be removed as required, you may be asked to clarify the use of any aspects of the data that may already exist in the public domain at the time of interview and when reviewing the transcripts.

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APPENDIX 5

CONFIDENTIALITY AGREEMENT (Transcriber)

I,

have accepted the task of word processing the research data collected by Martin Woods in order to complete a PhD at Massey University.

I understand that the data gathered for this research is confidential, and agree to take all necessary steps to ensure that any material on cassette tapes¹ or computer disk² containing data from interviews relating to the research will be:

- a) Heard only by me, and transcribed to disk in private¹
- b) Stored safely until returned to the researcher^{1,2}
- c) Removed from my hard drive after each transcribing session²
- c) Treated as confidential in all respects.

Signed

Witnessed

.....

Date

APPENDIX 6

A selection of national media/newspaper/radio references (in order of publication date)

Author	Headline	Year	Source	Details
Cleave, L.	Parents dice with boy's life.	1999	New Zealand Herald Online	12/02/99 http://www.nzherald.co.nz/print.cfm?objectid=2425
Collie, J.	Parents beg to be left alone.	1999	New Zealand Herald Online	13/02/99 http://www.nzherald.co.nz/search/story.cfm?storyid=CE8D8E32-39
Keane, P. & Newth, K.	Don't force boy's chemo, says advocate.	1999	Sunday Star Times	14 February, p. A1
Dearnaley, M.	Cancer family may have fled with pulse machine.	1999	New Zealand Herald Online	25/02/99 http://www.nzherald.co.nz/search/story.cfm?storyid=D31EFEAE-3
Perry, K.	Liam comes in from the cold.	1999	New Zealand Herald Online	07/05/99 http://www.nzherald.co.nz/search/story.cfm?storyid=F3508AE4-39
Ansley, B.	Mind that child.	1999	New Zealand Listener	22 May, pp. 18-20
Wall, T.	Parents put boy's cancer into hands of god.	1999	New Zealand Herald	12 October, p. A1
Wall, T.	Liam case worried Mangere boy carers.	1999	New Zealand Herald Online	15/10/99 http://www.nzherald.co.nz/section/story.cfm?c_id=1&objectid=15000
Grunwell, R. & Alexander, M.	Doctors told to get tough on parents.	1999	Sunday Star Times	17 October, p.A1
Johnston, M.	Teen backs chemotherapy.	2000	New Zealand Herald	3 September, p.A2
McLoughlin, D.	Liam Williams-Holloway and the triumph of quackery.	2000	North & South	February, pp. 72-81.
Mold, F.	Research seeks to reduce parent-doctor conflicts.	2000.	New Zealand Herald	4 December, p. A11.
Martin Y.	Claims of breach in Liam's case.	2000.	The Press	10/11/00 http://www.stuff.co.nz/inl/print/0.1103,478007a1561ff.html
Editorial	Little boy's death leaves last lesson.	2000	New Zealand Herald	28 October, p. A2
Maling, N.	Dob in a doctor could be law.	2000	Sunday Star Times	18 June, p. A3.
Johnston, M.	Cancer boy dies after lack of care.	2000	New Zealand Herald	25 August, p. A2.

Taylor, P. & Chisholm, D.	Suffer the little children.	2000.	Sunday Star Times	27 August, pp. C1, C10.
....	Family weep at cancer boy verdict.	2000	New Zealand Herald Online	24 August, p. A1. http://www.nzherald.co.nz/search/story.cfm?storyid=7A041CA8-39
Larkin, N.	Parents' agony over son they loved to death.	2000	New Zealand Herald Online	25 August, p. A11 http://www.nzherald.co.nz/search/story.cfm?storyid=787D4418-39D
Johnston, M.	Use courts to hit lagging parents.	2000	New Zealand Herald Online	26/08/00 http://www.nzherald.co.nz/section/story.cfm?c_id=1&objectid=149109
....	Liam's parents not alone in cruel cancer dilemma.	2000	New Zealand Herald Online	16/11/99 http://www.nzherald.co.nz/print.cfm?objectid=102613
....	Defence asks why cancer boy was not made court ward.	2000	New Zealand Herald Online	17/08/00 http://www.nzherald.co.nz/section/story.cfm?c_id=1&objectid=148078
....	Police did not consider charging Starship staff.	2000	New Zealand Herald Online	18/08/00 http://www.nzherald.co.nz/section/story.cfm?c_id=1&objectid=148189
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NZPA	Untested legal minefield awaits doctors.	2002	New Zealand Herald	7 June, p. A3.

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NZPA	Dead baby's parents charged.	2004	New Zealand Herald	27 February, p.3
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....	Prayer couple committed to trial.	2004	Newstalk ZB (Radio)	16/12/04 http://www.newstalkzb.co.nz/newsdetail1.asp?storyID=64090
NZPA	Baby dehydrated before death, nurse tells hearing.	2004	New Zealand Herald	16 December, p.A5
Northern Advocate	Couple tried to pray son back to life, court told.	2004	New Zealand Herald Online	17/12/04
NZPA	Family prayed to revive dead baby, court told.	2004	New Zealand Herald	18 December, p.A11
NZPA	Parents failed to get help for baby.	2005	New Zealand Herald Online	01/11/05
NZPA	Parents of dead boy not negligent, says lawyer.	2005	New Zealand Herald Online	17/11/05 http://www.nzherald.co.nz/search/story.cfm?storyid=00082A48-9B7
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Hartley, C.	Couple weep with relief.	2005	New Zealand Herald	19 November, p. A5
Harley, C.	A day after this picture was taken, Caleb Tribble dies.	2005	New Zealand Herald	19 November, p.B1

APPENDIX 7

Complementary and Alternative Health: A list of therapeutic applications and methods (New Zealand Ministerial Advisory Committee)

Action potential stimulation therapy Acupuncture

Alexander technique

Anthroposophical medicine

Applied Feng Shui

Applied iridology

Aromatherapy

Aura-soma colour therapy

Ayurveda

Bach flower remedies

Bio energy therapy

Biological medicine

Body electronics

Bowen therapy

Caeteris body/mind energy balancing

Chi Kung Chinese herbal medicine

Chiropractic

Colon hydrotherapy

Colour therapy

Craniosacral therapy

Crystal therapy

Dynamic phytotherapy

Educational kinesiology

Feldenkrais

Flower essence therapy

Gentle therapeutic manipulation therapy

Hellerwork

Herbal medicine

Holistic animal therapy

Holistic pulsing

Homoeobotanical therapy

Homoeopathy

Human potential
Hypnotherapy
Ifas
Intuitive healing Iridology
Isopathy
Jin Shin Jyutsu
Kinesiology
Maharishi's Vedic approach to health (Maharishi Ayur-Veda)
Massage (therapeutic and remedial)
Medical herbalism
Medium channel/intuitive healer/medium
Natural healing sciences
Naturopathy
Neurofeedback (LEG biofeedback)
Neuro-linguistic kinesiology
Neuro-linguistic programming (NLP)
Oriental massage
Ortho-bionomy
Osteopathy
Paramedical aesthetics and aesthetic medicine
Pacific traditional healing methods
Pilates-based body conditioning
Primal healing
Psychotherapy
Rebirthing
Reflexology
Reiki
Rife therapy
Rolfing (structural integration)
Sclerology
Shiatsu
Spiritual healing
Sports therapy
Touch for health test method