In Search of Self –

The Hospitalisation Experiences of Children with Cancer

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There comes a time when we are faced
with letting go all that feels important to us,
so that we may fly on the winds of life.

In turn we set free that which we have held important
so that it too may soar
into its own power and fulfil its potential.

That time has come for me.

I open my heart to the will of life that is deep inside of me,
and send forth across the heavens a cry of pain and sorrow that soars
on the wings of opportunity as I set myself free.

- author unknown

ABSTRACT

Cancer is the second most common cause of death in children in the Western world. The diagnosis and treatment process is painful and distressing, and is carried out in the hospital environment. This environment is foreign to most children, and influences children's coping with the experience of having cancer. Research in this area has focussed on assessing coping responses, and designing interventions for the pain, distress and anxiety associated with the medical procedures. There have also been studies which have measured the prevalence of emotional and behavioural difficulties in children with cancer. No studies have been conducted into children's experiences of hospital expressed in their own terms. The aim of the present study was to elicit the hospital experiences of children with cancer. Interviews were conducted with seven children, aged 5 - 15 years, who had completed treatment for cancer within the previous two years. An interpretive phenomenological design was utilised in order to gain and analyse accounts of the participants' perceptions and experiences. Findings suggest that the experiences can be interpreted in terms of two themes underlying the experiences of children with cancer, and their coping responses. The first theme is 'Retaining a sense of self-as-normal', which describes efforts to 'Maintain links with familiar people' and 'Becoming 'at home' in hospital'. The second theme is 'Incorporating multiple selves', which are 'Self-as-body-in-pain', 'Self-as-confined', 'Self-as-patient' and 'Self-as-survivor-living-with-cancer'. Success in retaining a sense of self-as-normal both affects, and is influenced by, the incorporation of multiple selves. Implications of these themes for practice in terms of the assessment of coping responses, design of interventions, and the measurement of outcomes, are suggested.

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CHAPTER ONE

INTRODUCTION AND BACKGROUND

> "Cancer in children is relatively rare…with about 120-140 children per million less than 15 years of age being affected annually. However, cancer is the second most common cause of death in childhood…in the industrialized world" (Corbett, 1995, p.7).

The latest available figures for New Zealand (Ministry of Health, 1999, p.54) show that 139 children, aged birth to fifteen years, were diagnosed with cancer in 1995. Of those, 78 were in the 5 - 15 year age range, which corresponds to the age range for participants in the present study. The current study was designed to elicit and examine the hospital experiences of children with cancer. The accounts were used to analyse the ways in which children cope with their hospital experiences, and in particular how their ways of coping reflect the seeking out of control, meaning and support. These issues were seen as contributing to understandings of the hospital experiences of children with cancer.

Understanding the hospitalisation experience of children with cancer can be of benefit in many ways, including dealing with issues of protocol compliance, disparate reactions to treatment, and psycho-social adjustment, both during and after treatment. One way of understanding the hospitalisation experience is by examining the coping strategies used by the children. These strategies reflect children's perceptions of control, support and meaning. For example, perceptions of control may influence the degree of protocol compliance (Miller, Sherman, Combs, and Kruus, 1992), as a child who feels they have at least partial control over their pain, distress or treatments may be less likely to utilise aggressive and avoidant strategies (Ellis and Spanos, 1994). The support available to the children can influence both their physical and psychological functioning in response to the cancer experience (Quittner, 1992; Varni, Katz, Colegrove and Dolgin, 1994). Support which may positively impact the child could be in the form of health professionals conferring with the child about treatment, or peers maintaining contact during long periods of hospitalisation. Support which may hinder the child's coping, could be the presence of a parent who is unable to cope with the stress of diagnosis or treatments. Finally, the meaning children with cancer attach to both the disease and the treatments can influence their choice of coping strategy, which in turn can affect their recovery rates. Open communication plays a role here by assisting children to understand, to the best of their cognitive ability, what cancer is, and how it will be dealt with (Claflin and Barbarin, 1991).

The aim of this chapter is to provide the context within which the children's accounts are situated. The central core of the context is the cancer experience which consists of two main aspects. The first aspect is the disease itself: What is the nature of cancer in children? Where and how is it treated? These questions will be briefly answered, and linked to the psychological construct of coping, with particular emphasis on control, support and meaning. The second aspect of the cancer experience is the environment within which diagnosis and treatment occur. The context of the children's accounts - the hospital environment – contains a unique arrangement of physical space, people and language which constitute a major change in the landscape of the children's lives. This unique arrangement will be outlined along with the possible effects on the children in terms of the psychological constructs of coping, control, support and meaning.

THE CONTEXT OF THE EXPERIENCE

Childhood Cancer - The Nature of the Uninvited Guest

The unexpected visit of cancer upon a child does more than interrupt the day-to-day business of living, it brings its very existence into question! To begin to comprehend the psychological impact of cancer on a child's functioning, at least a basic knowledge of the nature of cancer is necessary.

Cancer is a disease which occurs when the constant process of cell division in the body becomes abnormal, or uncontrolled. A characteristic of many cancers is that they grow (invade) and may spread to other parts of the body (metastasise). These two characteristics define a malignant tumour. There are many different forms of cancer which are graded in severity from 1-4, with 4 having the poorest prognosis.

The most common type of cancer in children (33% - 50%), is **leukemia** (Corbett, 1995). Leukemia affects the white blood cells which function to fight infection and provide immunity. The uncontrolled multiplication of cancer cells in the bone marrow not only affects production of white blood cells, but also red blood cells (which carry oxygen), and platelets (which help blood to clot). There are two types of leukemia: **ALL** (Acute Lymphoblastic Leukemia) and **AML** (Acute Myeloid Leukemia). **ALL** accounts for 80% of children with leukemia and has a better cure rate. **AML** accounts for the remaining 20%, and usually has a poorer prognosis (Ekert, 1989).

Brain tumours (20%) are the second most common cancer in children (Corbett, 1995). There are different types, and prognosis depends on the site affected, the structure of the tumour, the rate of growth and the degree of spread. Other types of cancer which affect children are:Hodgkin's Disease and Non-Hodgkin's Lymphoma (12%), Wilms' Tumour (6%), Neuroblastoma (7%), Osteogenic and Ewing's Sarcoma (5%), and cancers of miscellaneous sites (6%), for example, Retinoblastoma, and Rhabdomyosarcoma (Corbett, 1995).

Treatment of any cancer is focused on killing the cancerous cells and inducing remission – that is, no obvious evidence of disease through laboratory and physical checks. There are four modes of treatment – chemotherapy, bone marrow transplant, surgery, and radiotherapy – and each individual's protocol (treatment plan), may involve various combinations of these.

Leukemia is usually treated with chemotherapy and, in some cases, with a bone marrow transplant. ***Chemotherapy*** is a process involving the administration of toxic drugs - orally or intravenously. These drugs aim to kill the cancerous cells, but they also kill other cells in the body which multiply frequently, such as the cells of the bone marrow, the gut, hair follicles and reproductive organs.

A ***bone marrow transplant*** is used in the treatment of leukemia, or other childhood cancers, when chemotherapy and radiation are needed in such lethal doses that the patient's bone marrow is destroyed. The patient's bone marrow is replaced with healthy bone marrow either from a donor, or their own, which was taken at an earlier stage when it was healthy. After the transplant, the child must be in isolation for at least 3-8 weeks, while the new bone marrow establishes itself and rebuilds the immune system.

All the other various types of cancer previously mentioned may be treated with chemotherapy, but the treatment protocol may also involve either surgery or radiotherapy, or both. ***Surgery*** is the simplest way to remove cancerous cells. "In childhood cancer surgical removal of the main cancer site is usually the most desirable approach in dealing with the bulk of the cancer because, in the long term, surgery has the least number of undesirable long term consequences" (Ekert, 1989, p.19).

Radiotherapy utilizes radiation to kill cancerous cells. This method is commonly applied to tumourous cancers as they are localized in nature. "Radiation therapy is most effective in eradicating cancer when the cancers are small rather than large. It is often most effective in ensuring total cancer cell kill at the local site of the cancer's growth after the bulk of the cancer has been decreased by surgery or chemotherapy" (Ekert, 1989, p.22). Sometimes radiotherapy is used for the control of symptoms rather than cure, that is, palliative care.

Current treatments for cancer are widely available but are often painful, stressful, physically taxing and invasive. According to Barbara Shapiro, M.D., Associate Director of The Pain Service at The Children's Hospital of Philadelphia, "Children tell us again and again that the procedures are the worst part of having cancer" (Bain, 1995, p.115). For example, many diagnostic and treatment procedures involve venepuncture, where a device is inserted into a vein to either draw blood, or inject chemicals directly into the blood stream (Ekert, 1989). No child can escape this experience, which is invasive and painful. Venepuncture can range from the relatively quick finger 'prick' to bone aspiration. A brief definition of these procedures follows.

A ***finger prick*** is where a small amount of blood is collected after piercing the skin of a finger with a sharp needle. When treatment needs to be injected, an ***intravenous line***

(I.V.), may be used. This is where a needle is inserted into a vein, generally in the back of the child's hand, and then attached to a line from a drip containing saline, blood products, chemotherapy or other drugs. As an alternative to the I.V., two devices have been designed to minimize the stress involved in obtaining venous access – the Hickman line or catheter, and the portacath.

A ***Hickman*** is a tube inserted directly into the skin and then fed under the skin along the chest wall into a major blood vessel in the neck through to just above the heart. One end of the tube protrudes from the child's chest and is used for administering treatment and drawing blood, minimizing the need to 'prick' the child each time. A ***portacath***, though similar to the above, is a device surgically implanted under the skin and has no protruding tubes. Needles are injected through the skin into the centre of the portacath. This device has the advantage of being waterproof, less prone to infection and less obvious than the Hickman. Unfortunately, it does require that the skin be pierced each time.

For diagnostic purposes either of the two following procedures may be utilized. A ***lumbar puncture*** is a spinal tap, (type of needle), which is inserted through the ligaments and membranes surrounding the spinal cord in the lower back and cerebro-spinal fluid is withdrawn for analysis. For some children, this procedure may also be the mechanism for selected chemotherapy drugs to be injected directly into the central nervous system. A ***bone marrow aspiration*** involves the insertion of a needle into the top of the child's hip-bone, at either the front or back near the spine. Bone marrow is withdrawn to be tested for the presence of cancer cells. Both the lumbar puncture and the bone aspiration are painful procedures, which can create great anxiety for the children, parents and medical personnel.

A central characteristic of cancer in children is that it is unbiased in who it touches and where it touches them. Cancer affects

> "children of all shapes, sizes, colours, [ages, gender, socio-economic status, and from different family configurations]…cancer doesn't play favourites…And just as the children are different, so,

> too, are their diseases. From the top of the head to the tips of the toes, children's cancer can affect any part of the body" (Bain, 1995, p.8).

Because cancer is indiscriminate, unpredictable in its course, and variable in form, its effects are also indiscriminate, unpredictable, and variable in form. The effect of cancer and its treatments on the child can be both short and long term, and can affect the individual physically, intellectually, psychologically or socially. Each child will be affected differently and "periods of health and relative stability may be followed by periods of relapse and more aggressive treatments" (Eiser, 1990, p.3). The side-effects are related to the child's individual characteristics (physical, intellectual, emotional and spiritual), treatment plan, and type of cancer, and are also relatively unpredictable.

Side-effects form yet another unpleasant part of the cancer experience for the child, and can sometimes persist for years. Included in the list of **physical** side-effects are: nausea, vomiting, fatigue, anaemia, mouth ulcers, low immunity, hair loss, loss of appetite, liver damage and weight gain. (See Appendix A: Common side-effects of cancer treatments.) The effects of cancer treatments have implications for children's coping which will be explored in Chapter Two.

Medical success has created a generation of survivors, for whom hospitals have been a significant part of their lives; but, as outlined above, "despite the many successes ...current therapy is less than ideal - it sometimes causes much suffering and it still doesn't always work" (Bain, 1995, p.107). Bearing that in mind, it is surprising that there is a relative lack of research which focuses on children's understanding of their medical experiences (Genevro, Andreassen, and Bornstein, 1996).

The children's lives are no longer forfeit, but for the new generation of survivors, there exist issues of adjustment. While "a good clinical outcome is unarguably a paramount requirement of any clinical intervention, a good psycho-social outcome is of equal importance, and cannot be separated as a primary goal" (Child Cancer Foundation, 1998, cited in Stevens, 1999, p.24). Therefore, attention previously focused on physical concerns must now be broadened to examine the quality of life of the children through consideration of psycho-social issues such as:coping, control, support, and meaning. The current literature related to these issues for children with cancer will be discussed in Chapter Two.

Changed Landscape

The second aspect of the cancer experience is the hospital, the environment within which diagnosis and treatment occurs. As outlined above, the body of the child with cancer has changed from what it previously was, but some of the most significant changes which occur are in the taken-for-granted context of the child's life – the landscape – which has been abruptly and severely altered. "Although current practice is to reduce the incidence and duration of hospital stays as far as possible, the majority ...[of children with cancer] experience a greater number of admissions than healthy children" (Eiser, 1990, p.8). The landscape changes in the child's world include the physical environment, the people and the language. If diagnosed with cancer, this landscape may well be one in which the child will spend many days, weeks, months and possibly years visiting.

The Physical Environment

In New Zealand, at present, there are four hospitals where investigative procedures for paediatric cancer are conducted: Starship Children's Hospital in Auckland, and Wellington, Christchurch and Dunedin General hospitals. (At the time of writing, changes were occurring within the paediatric field nationally, and Dunedin hospital was being phased out as a tertiary provider). What are the psychological implications for the child of the geographical placement of the tertiary centres?

One of the major implications is in terms of support. New Zealand has a geographically spread population making it necessary for the sick child and family to travel to a tertiary centre for diagnosis, the initial development of a treatment protocol, possibly for ongoing treatment, and for check-ups. For some families they must travel long distances to reach a tertiary provider, and in the New Zealand situation that distance from a tertiary service provider can result in longer hospital stays (Stevens, 1999).

Subsequently, at a stressful time when social support is most needed, the child and family may be separated from the nuclear family, extended family, and peer supports. This separation can lead to a feeling of isolation and a belief that those left behind cannot possibly understand what those in the hospital are going through; the longer the period of separation, the stronger the sense of isolation.

The child's sense of control is also affected at this time. In the face of the unknown, or when feeling threatened, we prefer to be on our own home territory, surrounded by objects which are familiar, and routines where we know what is expected of us. The familiarity of our home territory imparts a sense of control over at least part of our experience. For children with cancer, and doubly so, for those who must travel to another town, this security is not available – there is no retreat to a safe home after news of the diagnosis. Even for those families fortunate enough to live in close proximity to a tertiary provider, the hospital environment and circumstances render the situation far from familiar.

As time progresses, the word 'hospital' comes to represent routines, antiseptic smell, the paediatric ward, the cafeteria, the outpatient clinic, the radiotherapy department, the radiography department, the haematology dept, the prosthesis dept, and surgery – to name a few. Life takes on a new momentum, albeit with a different focus and different routines. Hospitalisation has implications for the child in terms of coping as self-esteem and socialization skills may be negatively influenced through extended periods of isolation from family, peers and normal social settings, and from the need to adjust to the rules and routines of a new place.

The 'new' environment – the hospital – has as its reality limited space, minimal privacy and little control over noise. During this time "some of the more routine aspects of child-care become more complicated, time-consuming and emotionally laden" (Eiser, 1990, p.1). An example is the disruption that a Hickman can cause to the simple routine of keeping a child clean. A Hickman protrudes from an opening in the chest which must be guarded against infection due to its connection direct to the heart. As a result, the site must be kept dry so showers and deep baths are not possible. Shallow baths or sponge baths are the only options, options which do not always meet with the approval of the child, as they necessitate the assistance of either a parent or nurse. This may not be an issue for younger children under the age of six years, but older children may resent the lack of independence.

The hospital environment also challenges children's meanings and understandings. For instance, previously held views of doctors as people who make you feel better may be seriously tested as a child continuously vomits after being given chemotherapy prescribed by the doctor. Another example is related to the view of parents as protectors. This understanding is challenged as children may come to see their parents as allowing, and often giving physical assistance to, medical personnel who do 'bad' things to them, as in the case of a child needing to be held down for a lumbar puncture.

The People

The child with cancer is thrown headlong into a predominantly adult world where parents and health professionals hold much influence, other children are seen as a health risk, and the views of society influence the reactions of those who come in contact with them. The inhabitants of their world present a paradox as "each of the persons or social forces who might be a source of support…may also be a source of added stress" (Chesler and Barbarin, 1987, p.40).

***Parents*:** Parents, those people who are both bane and blessing during a normal childhood, come to be seen as anchors in a world gone topsy-turvy. For the child with cancer their parents may be the only constant in their life. This has implications for support and coping. Issues of attachment, which may have been successfully resolved at an earlier age, reappear and become problematic; for instance when a six-year old child becomes anxious to the point of hysteria if their mother must leave the room.

Parents may also be the primary means of coping, by offering a safe outlet for emotions. For example, a child may divert anger against an infection which has resulted in hospitalisation, either at the parent who is either the primary caregiver, or the absent parent. In this way, the child is able to release their anger, without concern for repercussions, or increasing their vulnerability to 'strangers'. Various modes of coping will be discussed in Chapter Two.

The hospitalized child is required to redefine the roles in their relationship with their parents, and there are many inherent contradictions in this situation. One such contradiction, as mentioned before, is that of 'parents as protectors' and 'parents as perpetrators'. A second contradiction is that of 'children as dependent on their parents' and 'children as protectors of their parents'. In my role as a companion for Camp Quality, I often visit children and their families in hospital. I have a memory which has stayed with me for twelve years, of an eight-year old child with stage four leukemia saying: "I can't go yet, mummy isn't ready." The child, as both 'dependent' and 'protector', has implications for control and support, which will be discussed in Chapter Two. While parents form the central adult presence in a child's life, health professionals are also a significant presence, making up the second dominant group in this adult-dominated world.

***Health professionals*:** "Although the behaviors of health care providers clearly have a significant impact on the perceptions and behaviours of children with a chronic illness, this area of prevention appears to have received the least amount of attention" (Harbeck-Weber and McKee, 1995, p. 179).

Once the diagnosis is confirmed, the severity of the condition results in swift treatment over which the child has little or no control. During this time the child will come into contact with a wide range of health professionals including: phlebotomists, radiographers, nurses, paediatric oncologists and surgeons. Each one of these people plays a role in diagnosis and treatment and will be physically interacting with the child in various ways. Sometimes the child has limited understanding as to what is occurring. The lack of understanding may be due to several factors: inadequate information; parent's express wish that their child not be told the full story; information presented at a developmentally inappropriate level; lack of time for the child to absorb information; an inability to focus due to feeling sick or in pain; or a lack of confidence by health professionals and families to know how best to talk with the child.

When we deny the child access to both information and the decision-making process, we compromise their ability to cope, their ability to recognize those to whom they can turn for support, and their involvement in their own healing. Children require the maximum information about the current situation, taking into account their developmental age. "To shield the child from the truth may only heighten anxiety and cause the child to feel isolated, lonely, and unsure about whom to trust" (Sourkes, 1995, p. 33). Open and honest communication allows the children the opportunity to express anxieties, fears, hopes and wishes, not only about what is happening to themselves, but also what they perceive to be occurring to those around them.

If inadequate communication occurs, health professionals can come to represent a negative stimulus representing painful treatments where the child has limited understanding and control. The serious issue of non-compliance with treatment protocols may be related to inadequate involvement of the child. In contrast, medical professionals, able to converse with children at an appropriate level, are able to develop a relationship of trust in which the child feels secure, able to voice concerns and opinions, and request information.

***Support people*:** One group of adults who may form a central part of the support network, within the changed landscape, are members of the extended family. Under normal circumstances, it is often the case that a child may only see extended family infrequently. The cancer diagnosis may result in regular visits, even the long-term presence of extended family, in the family home, while the child is hospitalized. How does the child make sense of these changes? Are they threatening? And if the relative is popular, and moves out as soon as the child comes home, does the child think they have done something wrong?

The child may also be introduced to the school teacher, social worker, psychologist, Child Cancer Foundation family support coordinator and friends/colleagues of their parents whom they have never met. The range of new people entering their lives, and their hospital room can be a very confusing and intimidating experience, which calls on energy levels already taxed by cancer and its treatments.

***Children*:** While the numbers of adults in the child's life increase sharply, the number and visibility of other children can sharply decrease. The child, whether in hospital or at home, needs to be protected from infection and injury, and therefore visitors are closely monitored. Also, as noted earlier, travel to a tertiary centre may preclude the possibility of friends and siblings visiting. Long periods of hospitalisation and periods of poor health result in reduced school attendance, and the separation from peers and teachers. The resulting isolation has implications for the child's ability to cope and make sense of these changed circumstances. For example, what are the possible interpretations a child might make when friends and siblings don't come to visit?

Language

The language of cancer is technical and foreign; it has no place in the daily lived experience of the child untouched by cancer. It is a language which must be learned from scratch, and is predominantly a language of pain and uncertainty.

The understanding, or at least familiarity with this new language, can greatly assist a child's ability to cope. Uncertainty and anxiety can be avoided to a certain degree if the child is told they are to have a lumbar puncture and they understand the steps of the procedure and what is expected of them. If they are unfamiliar with the procedure, the sight of the needle, the discomfort of remaining curled in the fetal position, and the fact that they cannot see what is happening, can all be very alarming. Ease and familiarity with the vocabulary of cancer and its treatments can also lead to a greater ability for the child to share with family and medical professionals their perceptions of their experience – how they feel about certain procedures and/or medications.

Meaning-making is also implicated with a new language. Language is one means by which we gain understanding and knowledge of our world, and ourselves (Freeman, Epston and Labovits, 1997) with a new language, misunderstandings can easily occur creating confusion and sometimes, unnecessary anxiety. A sense of control may be imparted to the child if they are able to understand the procedures and treatments to a level where they can make decisions related to their own health. For example, a child may come to know the dose of Pamol required to bring down their temperature, and also when the next dose is due. Or, when feeling nauseous, they may suggest use of a medication which they feel was most effective in the past. Increased control allows the child to be an active participant in their treatment and can result in a sense of increased support and collaboration, providing the child with a vested interest in the results of treatment. The important role of open communication and collaboration will be further discussed in Chapter Two.

SUMMARY

The aim of this chapter was to provide a very brief outline of the essential elements of the hospital experience of the child with cancer. This background is necessary for the sketching of possible ways in which the context (that is, the hospital and the physical aspects of cancer), can be understood as the focus, or target, for coping strategies. This knowledge also points to the possible ways in which control, support and meaning, as elements of coping strategies, may operate as protective factors in the perception and experience of stress, thus affecting the psychological development and adjustment of children with cancer. It also provides a frame of reference for the research pertinent to the areas of paediatric oncology and coping, which will be reviewed in the following chapter.

CHAPTER TWO

THE LITERATURE

In the previous chapter elements of the hospital context were outlined, and the implications of this context for coping - specifically in terms of control, support and meaning - were briefly alluded to. In this chapter, research in the area of coping with the paediatric oncology experience will be reviewed and discussed, with particular emphasis on the implications for perceptions of control and support, which are frequently referred to in the empirical literature. The implications for perceptions of meaning, which are implicit throughout the studies reviewed, will also be described. A brief discussion of conceptual and methodological issues in the research literature is included at the end of this chapter.

The research literature on coping in children with cancer, which has implications for hospitalisation experiences, falls into three groups. The first looks at the styles of coping responses to medical treatments. The second group of studies focuses on behavioural coping responses to the distress and pain of medical treatments for cancer. The final group is concerned with the efficacy of coping responses, assessed indirectly by measures of psychological adjustment. The aim of this chapter is to look at the contribution of the literature to our understanding of the ways in which children cope with the demands of hospitalisation, as part of the cancer experience. A definition of what is referred to as coping, and of the 'coping episode', follows. This information forms the foundation from which the literature may be examined.

COPING AND THE COPING EPISODE

The dominant conceptualisation in the field of coping is provided by Lazarus and Folkman (1984). They define the nature of coping as a dynamic, multi-faceted process brought to bear in response to a perceived threat, challenge, or loss in a given situation. This process involves the interaction of individual appraisals of the situation, and perceptions of the resources available to master that situation. Rudolph, Dennig and Weisz (1995), propose three elements as forming part of the ensuing 'coping episode' - a coping response, the coping goal underpinning that response, and the coping outcome.

A *coping response* is an intentional action, physical or mental, carried out in response to a perceived threat or stressor. These responses can be described in two ways: as strategies, and as styles. Coping strategies are the actual coping methods (e.g. seek support), and represent a micro-level approach, which is situation-specific. Coping styles, on the other hand, are a macro-level approach to categorising coping responses, and may contain several strategies under their umbrella. The coping styles represent inherent individual tendencies to respond in a particular way, over a range of situations; for instance, a child who responds with physical behaviour to every perceived stressor. Coping styles have been categorised in several ways in the literature on coping in adults, but only behavioural vs cognitive, primary vs secondary, and approach vs avoidance appear in literature related to paediatric oncology patients.

Behavioral Vs Cognitive Coping seeks to distinguish between behavioural responses, (e.g. muscle relaxation), and cognitive responses, (e.g. positive self-talk). The former is measured using observational measures, while the latter is assessed by with self-reports. *Primary Vs Secondary Coping* defines three response categories, which draw on research conducted with adults in the field of perceived control (Rudolph et al., 1995). Primary control is viewed as coping designed to alter objective events or conditions, while secondary control is aimed at adjusting oneself to the demands of the situation, and relinquished control represents the absence of coping efforts (Rothbaum, Weisz, and Synder, 1982; Weisz, 1990).

The last classification of coping responses, *Approach Vs Avoidance*, seeks to locate coping responses along a continuum of approaching the perceived threat, or avoiding the situation. The continuum has also been referred to as information-seeking versus information-avoiding (Peterson and Toler, 1986), active versus passive (Peterson, 1989), repression versus sensitization (Byrne, 1964), high and low blunting (Miller 1987a), and high and low monitoring (Miller, Brody and Summerton, 1988).

The desired outcome of the coping response is referred to as the *coping goal*, which is generally aimed at neutralising the threat of a situation, and managing the associated emotional distress. No literature investigating children's coping goals in paediatric oncology patients was found, although the information such studies could provide would be invaluable in clarifying the thought processes involved in children's coping.

Finally, the last element of the coping episode is the *coping outcome*, which relates to the impact of the coping response on the perceived threat. The impact is measured in terms of the efficacy of the response in attaining the coping goal, which has implications for the assessment of coping efficacy, and highlights the importance of multiple measures of coping. For example, parents may assess behaviour in terms of their own coping goal of reduced observed distress in their child, medical professionals may assess efficacy based on their goal of obtaining increased compliance, while the child may determine efficacy on the basis of attaining their coping goal of not tensing. The result may be three disparate assessments of the coping outcome.

Much of the conceptual work regarding coping has taken place within the adult arena, where cognitive processes and behavioural patterns are qualitatively different to those of children (Peterson, 1989; Siegel, 1992). Researchers are beginning to investigate the ways in which children appraise stressful situations, their proposed solutions, their choice of action, the execution of their plan and the evaluation of its efficacy. This is still relatively virgin territory and there remains much to be learned (Miller, Sherman, Combs and Kruus, 1992).

COPING MEASURES

Several measures have been commonly utilised within the reviewed literature on children with cancer, and are described here. The Procedure Behavior Rating Scale-Revised (PBRS-R; Katz, Kellerman and Siegel, 1980), and Observation Scale of Behavioral Distress (OSBD; Jay, Ozolins, Elliot, and Caldwell, 1983) were used to measure distress, and are behavioural checklists completed by observers. The Child Behavior Checklist (CBCL; Achenbach, 1991), is also a behavioural checklist, but one that measures adjustment. It is completed by parents and medical personnel. The Children's Depression Inventory (CDI; Kovacs, 1992), and the Self Perception Profile for Children (SPPC; Harter, 1985), are self-report measures also measuring adjustment, giving indirect evidence of the efficacy of children's coping efforts. The CDI is a symptom-oriented scale measuring depression. The SPPC has various sub-scales including Global Self-Worth, Physical Appearance, Social Acceptance, and Fear of Negative Evaluation, each of which has a different format, but which all ask the participants to rate their perceptions of themselves.

Preferred coping style was assessed using the Coping Strategy Interview (CSI; Tobin, Holyrod, Reynolds and Wigal, 1989), which asks children to respond to two open-ended questions designed to elicit coping strategies the children used during prior BMAs And LPs. The Children's Behavioral Style Scale (CBSS; Miller, 1987b) is a new scale, providing a downward extension of Miller's Behavioral Style Scale to children, and is designed to assess Monitoring-Blunting tendencies (that is, information-seeking Vs. information-avoiding), through response choices to four stress invoking scenarios. Finally, the Child-Adult Medical Procedure Interaction Scale (CAMPIS; Blount et al., 1989), is a coding measure for behaviours and interactions between parents, physicians and children, which occur during medical procedures. It is designed to indicate interactions which precede children's distress.

COPING STYLES

Few studies were found, within the paediatric oncology research literature, which explicitly examine coping styles and strategies. The studies found were concerned with examining both the determinants of style and their prevalence within paediatric oncology groups, sometimes providing comparisons with samples from the general population. The one study explicitly related to coping strategies examined both the prevalence and efficacy of the strategy employed. These are reviewed below.

The literature on coping in children with cancer indicates that disease chronicity may be a major determinant of coping style. Disease chronicity, that is, time since diagnosis, and previous number of procedures (Smith, Ackerson, Blotcky and Berkow, 1990), is viewed as a moderator of coping. A moderator is a "variable that affects the direction and/or strength of the relation between an independent...and a dependent...variable" (Baron and Kenny, 1986: p.1174). In the literature the independent variable is the coping response, and the dependent variable is the coping outcome. The moderator may either be a characteristic inherent in the child, (for example, disease chronicity), embedded in the stressor (for example, controllability), or embedded in the context (for example, parental influence) (Rudolph, Dennig and Weisz, 1995). The literature indicates that an avoidant style is more common in the early days of diagnosis and treatment. However, conflicting evidence exists as to whether the style employed by children alters with increased time since diagnosis, or remains the same.

Smith, Ackerson and Blotcky (1989), assessed the preferred coping style in 28 paediatric cancer patients undergoing bone marrow transplants (BMAs) and lumbar punctures (LPs); (these procedures were described in Chapter One). On the basis of the data collected using the CSI, children were assigned either repressor (information-avoiding), sensitizer (information-seeking), or mixed status. Repressors were found to be closer to diagnosis than sensitizers, and to have experienced fewer procedures.

In a later study, Smith et al. (1990), assessed the behavioral coping strategies of 44 paediatric oncology patients and confirmed their earlier results regarding coping style and disease chronicity. They found that 55% of children utilized information-avoiding strategies, 12% information-seeking, and 17% used mixed strategies. In addition, an avoidant coping style was more common in the early stage of diagnosis and treatment.

The possible importance of disease chronicity as a moderator of coping is further supported by the findings of Phipps, Fairclough, and Mulhern (1995). These researchers compared the coping style of 66 children with cancer with a normative control of 414 healthy children, using the (CBSS). Findings from the study of Phipps et al. showed children with cancer to utilize more blunting as a coping style, than the normative sample. However, in contrast to Smith et al. (1989), they found that use of blunting increased relative to time since diagnosis.

The findings of the literature related to coping in paediatric oncology patients are mixed, although some agreement exists for the dominant presence of an avoidant coping style during the early stages of diagnosis and treatment. The dominance of an approach style in the later stages of treatment is less clear. What are the possible explanations and implications of these findings?

Firstly, Smith et al. (1990) suggest that an avoidant coping style may be used in the early phases of treatment as, generally, there are a greater number of procedures than later in the process. It is also feasible that the child is suffering from information overload early in the diagnosis and treatment process, choosing to withdraw in order to assimilate the situation.

Conceptualised in this way, repression (blunting, or avoidance), represents a coping *response.* This is in contrast to recent studies of psychological adaptation, where repression has been interpreted as a negative coping outcome to the paediatric cancer experience (Canning, Canning and Boyce, 1992; Worchel et al, 1988). Repression as a coping *outcome* was posited to explain the unexpected findings of lower levels of self-reported depression in children with cancer compared to normative samples.

Secondly, the findings of Smith et al. (1989, 1990), of increased use of approach strategies with time since diagnosis may have less to do with disease chronicity than with the increased age of participants, and greater cognitive maturity. Evidence of developmental trends is found in the study of Phipps et al. (1995). These authors observed age/developmental trends with blunting behaviours decreasing with increasing age; this could indicate that blunting represents a less mature response than monitoring.

Tyc, Mulhern, Jayawardene and Fairclough (1995), also saw cognitive maturity as a possible explanation for their findings of age differences in self-reports of preference and effectiveness of coping strategies for nausea and emesis (vomiting). Results found resignation to be more frequently used by adolescents than preadolescents, while problem-solving was reportedly more effective for adolescent boys and girls, and wishful thinking was seen as more effective by preadolescents than adolescents.

As no analyses were done in the studies of Smith et al. (1989, 1990), in terms of age at diagnosis in relation to coping style, or differences in coping style in terms of exact time since diagnosis, caution should be exercised in interpreting the strength of the influence of disease chronicity on coping. Nonetheless, it would appear that disease chronicity does exert some influence, which has implications for the study of coping in paediatric oncology populations. The implications relate to the need for studies to take into account the individual child's condition which may vary in terms of the nature of onset, chronicity, severity of current symptoms, prognosis, and degree of physical impairment (Compas, Worsham and Ey, 1992). Due to the inherent nature of the individual child's physical status, it influences the appraisal of the controllability of stressors. This in turn influences the coping episode as controllability affects the coping goal, the choice of coping response, and subsequently the coping outcome.

Thirdly, the findings of the above studies may reflect methodological issues. In all of the above studies coping style was assessed through recall of coping responses used on previous occasions, therefore there may be an inherent bias in reporting. This could possibly account for Smith et al.'s finding (1989) that matching an intervention to preferred coping style for BMAs and LPs, resulted in higher self-reports of pain rather than lower.

Fourthly, as none of the above studies assessed coping responses during an actual procedure, it is difficult to assess what aspect of the procedure the children were responding to. Coping with medical procedures has come to be seen as a stage-like process involving anticipation, encounter, and recovery (Rudolph et al., 1995). Each of these stages is different in its demands on the child, and may necessitate different coping goals and responses. For example, the physically painful stage of the procedure - the encounter phase - may also be a source of distress. The coping response utilised would depend on the coping goal, which may be to reduce either the pain or the distress. In contrast, the anticipatory stage is not painful, but may be distressing, so the coping goal and coping response observed are likely to be aimed at reducing the distress.

Some studies have found relationships between coping style and adjustment, related to the particular target stressor. Weisz, McCabe and Dennig (1994), explored responses to four uncontrollable stressors associated with leukemia and its treatment - staying in hospital overnight, BMAs/LPs, vomiting, and hair loss - and children's level of adjustment. Findings showed a positive association between secondary control coping, general behavioural adjustment (assessed by the Child Behavior Checklist), and illness-specific adjustment (assessed by self-reports and behavioural observation). When children were grouped by coping response - primary, secondary or relinquished control - the secondary control group showed significantly better adjustment.

Weisz, et al. (1994) cautioned against generalizing these findings across stressors. There are stressors which are more controllable than others for each physical condition, and even within a single illness such as leukemia, stressors may vary in controllability. While secondary control may be adaptive in leukemia for uncontrollable stressors, it may be a maladaptive response to a more controllable stressor, such as interaction with peers.

An example of variable responses to stages within a procedure, was found in the study by Broome, Bates, Lillis, and McGahee (1990), which explored the relationship in 17 children with leukemia, between medical fears (measured with the Child Medical Fear Scale - CMFS), coping behaviours (observed and coded using Rose's Coping Assessment Tool), and self-reported pain perceptions, during a LP. On the basis of the behavioural coding, children were defined as exhibiting either passive or active coping styles during the five phases of the LP - pre-procedure, cleansing the site, numbing phase, LP phase, and post-procedure.

Findings showed that for many children active behaviours were prevalent during the first three phases, while passive behaviours increased during and immediately after the LP. Eleven of the 17 children used a combination of active and passive behaviours. It is therefore important to specify the stressor and to recognise the different demands which may be implicit in what may appear to be a single situation.

Finally, as all the studies asked for retrospective information, it is difficult to assess what influence coping style had on the *actual* experience of distress and pain before, during and after the procedures. Here again, Broome et al. (1990), offer some information. In their study they found children who exhibited passive coping behaviours during the preparation, cleansing, and numbing phases, reported more pain than those who demonstrated active coping behaviours. The implications for pain assessment include the incorrect assumption that passivity reflects the experience of less pain. An implication for interventions is the need to teach active coping techniques which encourage the child to exert a degree of control.

The remaining explicit studies in the area of coping and paediatric oncology relate to specific strategies and their effectiveness. Claflin and Barbarin (1991) found that choice of coping response was related to age. Younger children (under 9 years of age), preferring behavioural forms, middle children (aged 9 - 14 years), using behavioural and cognitive responses, while adolescents (14 years and older), used more cognitive strategies. In one of the few studies to focus on chemotherapy procedures in children, Tyc et al. (1995), investigated the preference and perceived effectiveness of coping strategies used to manage chemotherapy-induced nausea and vomiting in 57 children with cancer. KIDCOPE, an inventory containing various items representing active, avoidant and negative strategies, measured the use of coping strategies employed during a previous chemotherapy experience. Participants rated each item according to frequency of use, and efficacy. Participants were also asked to rate the degree of distress for nausea and vomiting associated with chemotherapy, on a 5-point Likert scale.

Results showed the most frequently used strategies for both nausea and vomiting to be emotional regulation, social support, distraction and wishful thinking; these were also seen to be effective. Interestingly the strategy reported as being the most effective for both nausea and vomiting - sleep - had lower rates of reported use, although the overall trend was for greater usage of the more effective strategies. All strategies were more effective in dealing with nausea than vomiting. Successful copers, defined by minimal distress and high efficacy ratings for their coping strategies, tended to use problem-solving and social support for nausea, while no specific strategies for vomiting were identified. Problem-solving was also rated as most effective for those further on in time since diagnosis. Finally, the strategy preference of patients, and their efficacy were related to the level of distress, that is, those reporting lower distress generally reported their strategies to have been effective.

The more frequently used strategies attempt to modify the self, and fall into the secondary control coping style, indicating that nausea and vomiting may be perceived as relatively uncontrollable stressors. The accuracy of this assessment of controllability is given some support by the ratings of efficacy of those strategies, indicating a fit between perception and response.

Social support, used frequently and found to be effective for most participants, was also found to discriminate between successful and unsuccessful copers. Although Tyc et al. (1995) do not discuss the significance of this, it may be that social support can be indicative of both a primary and a secondary control style, hence its frequency of use generally, and its position with problem-solving as a key strategy for successful coping. Social support could be seen as a secondary control response if the coping goal is to distract oneself by holding someone's hand; in contrast, social support may be a primary control response if the coping goal is to change a parent's distant behaviour. It may also be the case that social support is a resource which children use for coping and its presence is needed to effect a coping response.

Interestingly, one of the indicators of successful coping - problem-solving - was not one of the more common strategies used, and is representative of an approach coping style; nor was the use of problem-solving reported by any of the unsuccessful copers. This indicates two points. Firstly, problem-solving is not a naturally occurring response, and may require both training and a certain level of cognitive maturity. Secondly, a change in perception of the controllability of the stressor is required for strategies to shift to an approach style, which may explain why problem-solving is used by those children who are at a greater distance from diagnosis. This study provides some support for the idea of secondary control, or an avoidant coping style, being primarily utilised and effective in the early stages of diagnosis and treatment, while a primary control, or an approach coping style, is utilised and effective further into the treatment process.

The emetogenic potential (that is, likelihood of causing vomiting), of the chemotherapy protocol may have implications for the assessment of controllability, where low to moderate emetogenic potential may be dealt with using primary control (that is, responses aimed at changing an element of the situation), while high emetogenic drugs may best be dealt with using secondary control (that is, changing the self to the demands of the situation). Emetogenic potential may also influence coping responses as highly toxic agents may also require stronger anti-emetic drugs, which have a sedative effect, thereby interfering with the ability of the individual to maintain sufficient control to implement coping responses.

As stated earlier, coping research in the area of paediatric oncology can be divided into three broad categories. The following studies relate to the latter two categories: behavioural coping responses to the distress and pain of medical treatments for cancer, and the assessment of psychological adjustment. This body of literature provides indirect evidence for the efficacy of various coping styles and strategies.

COPING RESPONSES TO PAEDIATRIC ONCOLOGY MEDICAL TREATMENTS

From the time that cancer is suspected, a child can be expected to undergo a range of procedures to determine the presence or absence of cancer, each intervention being specific to the suspected form of cancer (Granowetter, 1994). The diagnostic procedures are usually painful and upsetting for the child and the parents, and are often repeated numerous times (Harbeck-Weber and McKee, 1995). Therefore the control of pain, distress and anxiety is an area of particular interest in paediatric oncology.

Before looking at this literature a brief discussion of pain, distress, and anxiety is needed. Historically, the clinical assessment and treatment of paediatric pain has been based on incorrect assumptions, including the belief that children feel less pain than adults, or have a heightened threshold (Eiser, 1990). This has led to inadequate assessment, under-medication and unnecessary suffering for many paediatric patients (Gaffney and Dunne, 1986; Zeltzer, et al. 1990; McGrath et al. 1990; McGrath, 1996). It is now acknowledged that these assumptions are unfounded, and efforts to effectively assess and treat children's pain have greatly improved.

Distress, used interchangeably with anxiety throughout the literature, is thought to both precede pain, and indicate its presence. While none of the studies reviewed offered a definition of distress, rating scales purported to measure distress included such behavioural items as: crying, vomiting, withdrawal, groaning, screaming, flailing and kicking. Thus there is an assumption that distress is manifest in children in observable behaviours, and adequately assessed in this way.

The example of behaviours listed above are problematic in that some items may be *both* indicative of the presence of pain, distress and anxiety, and be coping responses. For example, crying can be a reaction to pain felt during a procedure, while also representing a coping response if used prior to a procedure, with the purpose of eliciting social support. The possibility of items being both reactive and responsive to the situation being observed causes great confusion as the majority of studies do not indicate the sequence of behaviours, and children are not asked why they behave the way they do. Without information regarding the coping goals of the children, it is difficult to identify behaviours which could be said to represent pain, distress and anxiety. The result is that any interventions which aim to reduce so-called 'distress behaviours' (e.g. crying), during a procedure, may in fact be removing a coping response from the repertoire of a child.

The following research is concerned with the pain, distress and anxiety associated with the medical procedures common to the hospital experience of paediatric oncology patients. The first section covers research into the assessment of pain, distress and anxiety during medical procedures. These studies examine the incidence and prevalence of behaviours during procedures, factors influencing those behaviours, and the effect of different behaviours on observer and self-ratings of pain, distress and anxiety during the procedures. As noted earlier, the procedures do not represent a single situation, but are instead made of several phases, each of which makes different demands on the child. The studies reviewed varied in their focus, some included all parts of the procedure and split results according to the phases, while others made no distinction between the anticipatory, procedure and recovery phases.

The second section examines the efficacy of interventions aimed at reducing the pain, distress and anxiety associated with medical procedures. These studies evaluate the prevalence and generalisability of both naturally occurring, and coached, coping strategies. Coping outcomes are measured in terms of reductions in observer and self-reports of distress, pain and anxiety.

Behavioural Coping Responses during Procedures

In the area of paediatric oncology, much of the research examining coping with pain, distress and anxiety has focussed on bone marrow aspirations (BMAs), and lumbar punctures (LPs), although there are a few which are concerned with pain in general, or pain associated with chemotherapy procedures. BMAs, and LPs represent target stressors as they are widely seen by children with cancer as stressful procedures (Zeltzer, Kellerman, Ellenberg, Dash and Rigler, 1980; Broome et al., 1990). Ellis and Spanos (1994), in their review of interventions for BMAs and LPs, found that:

> "Children are not equally distressed by medical procedures... Factors that contributed to the variability of pain and distress behaviour included the age and gender of the child, the level of parental anxiety, the parent's anticipation of their child's pain, generalized fear of medical procedures, and coping style" (p.98).

Coping style has been discussed above, and medical fear was examined in only one study, previously mentioned, (Broome et al., 1990), in which medical fears existed but were not prevalent or severe in nature. The researchers did find, however, that children with higher levels of medical fears, also had higher perceptions of pain. Parental influence will be examined later in this chapter. The remaining factors - age, and gender - will each be discussed, and their implications for control outlined.

Age

In addition to the earlier reported findings of age differentiation in children's use of coping strategies (e.g., Tyc et al., 1995), consistent age differences have also been found in ratings of children's behavioural responses to stressful procedures (e.g., Kazak et al., 1996), and in children's self-reports of pain and anxiety (e.g., Manne, Jacobsen and Redd, 1992). The interpretation of these differences is less consistent.

In the study by Kazak et al. (1996), parents and staff were asked to rate children's and parents' stress, on 7-point Likert-type items, both before and during the procedures. They found that younger children were described by their parents and nurses as having significantly higher levels of distress *during* procedures than older children. There was no notable difference between younger and older children *prior* to the procedures. Physician ratings showed no age effect, and no measure of post-procedural distress was utilised.

Katz, Kellerman and Ellenberg (1987), used a more comprehensive rating scale, with 25 behaviours named and defined, for example: cry - tears in eyes or running down face. All ratings were conducted by independent observers, and covered four phases: anticipatory, preparatory, procedure, and rest period after the BMA. Results indicate that observers rate younger children as exhibiting more behavioural anxiety *during* BMAs, but also pre-, and post-procedure. This inverse relationship between age and anxiety was statistically significant, and was stronger for males than females. In addition to displaying more anxious behaviour, younger children were also observed to display a greater *frequency* of anxious behaviour.

The findings of the above studies suggest that, when utilising observer ratings of behaviours during BMAs and LPs, younger children will receive higher ratings for behavioural distress as they exhibit a greater frequency of distress behaviours. However, further interpretation of these findings regarding age differences in reaction to BMAs and LPs is limited, as the above studies relied on the perceptions of parents and nurses to gauge the degree of discomfort experienced by the child. Neither of the above two studies asked children for their rating of distress, so there is no information as to the correlation between observer ratings and self-report ratings of distress.

Those researchers who have utilised self-reports have also reported age-differentiation, although the reasons posited for these vary. In a study comparing child self-report, parent ratings, and nurse ratings of pain and distress during venipunctures, Manne at al. (1992), found agreement between self-reports and observer ratings of pain and distress. The major influence on children's self-reports of pain and distress was their age, with older children reporting less pain and distress. Further, observed distress significantly predicted their self-reported distress and pain ratings. Hilgard and LeBaron (1982), in contrast, found a significant difference between self-reported pain in children aged 10 years and over, and the observer ratings of pain, which typically underestimated the level of perceived pain. The authors suggest that children over the age of 10 years may have learnt to control their behavioural expressions of pain.

While this may be the case, Jay, Elliott, Katz and Siegel (1987), suggest that the behavioural expressions themselves may differ with age. In their study of 56 paediatric patients with leukemia, they found that although younger children did exhibit more overt distress behaviours, the self-reports of pain did not differ significantly from those of older children. The authors suggest that pain ratings would be expected to be similar, while behavioural expressions are thought to reflect developmental changes. Both interpretations could be true, as greater personal control over behaviours, could result in more subtle behaviours requiring more sensitive measurement tools.

Variation in behavioural responses according to age are clearly identified by the findings of Katz et al. (1980). They found that younger children (8 months - 6 years), express themselves more through crying, screaming, needing restraint, and verbal comments, reflecting the relative lack of inhibition common in younger children. Intermediate aged children (6 - 10 years) express pain verbally, cry, scream and hold themselves rigid; while the older children (10 - 18 years), express pain verbally and hold themselves rigid. These trends indicate a developmental tendency toward "less diffuse vocal protest and skeletal activity and greater emphasis on verbal expression along with increased muscle tension" (Katz et al. 1980, p.361).

The above studies suggest that the findings of age differentiation may be due to chronological age indicating the developmental level of a child, which may predict the understanding of procedures and ultimately the experience of pain and anxiety (Manne et al., 1992). In these terms, older children might be expected to evidence greater comprehension of the necessity for procedures, controlling overt behaviours which may result in a procedure taking longer, and being more painful. It may also be that Manne et al. found agreement between self-reports and observed distress due to a halo effect in the self-reports of older children.

The studies also indicate that the type, intensity, and frequency of behaviours during and after procedures is more an indication of developmental level, than actual distress. If behavioural differences occur as a result of developmental levels, then the measurement tools currently used for assessing distress and pain, may reflect an age bias towards the identification of distress in younger children. The implications for older children are that their distress may remain relatively unnoticed, with few interventions designed for their use, particularly if self-reports do not feature as part of the assessment process.

Gender

There have been conflicting results regarding gender differences in distress. Katz et al. (1980), found that females exhibited more behavioural distress, and reported higher levels of pain, than boys. There were also qualitative differences in the behaviours observed, with females more likely to cry, cling, and request emotional support, while boys were more likely to stall. They comment that it is difficult to know if these findings are due to differential socialization, or are representative of inherently sex-specific behaviour. Given these two possibilities it is surprising that few other researchers have found similar patterns.

An alternative explanation is that, rather than females experiencing more anxiety, there may be a gender bias in the measurement instruments, so that behaviours more likely to be utilised by boys do not appear on behavioural checklists. This would appear likely given the findings of gender differences in the frequency of behaviours, but not the efficacy of coping strategies, in the study by Tyc et al. (1995). Social withdrawal and cognitive restructuring were more frequently utilized by boys than girls, both of which could be less discernible to observers.

Girls were also found to exhibit more distress behaviours than boys in a study by Katz, et al. (1987), assessing the effectiveness of hypnosis in comparison to a non-directed play intervention, in assisting 36 children with leukemia to cope with BMAs and LPs. Furthermore girls benefited more from the hypnotic intervention, while boys benefited more from the play intervention. Previous research suggests that this may be due to girls, generally, being more verbally competent, and better able to concentrate (Berger, 1983).

While current results indicate that females may rely more on emotion-focused coping than boys, more research is needed to provide a clearer indication of the extent to which gender influences the experience of pain and anxiety.

The above findings of age/developmental differences in the type, intensity and frequency of distress behaviours, and gender differentiation in the frequency and type of distress behaviours, have implications for the coping episode. The coping goal (as the first aspect in the coping episode), relies on appraisals of the situation, part of which relates to the controllability of the stressor (that is, the degree to which the individual is able to direct the occurrence of events). As outlined earlier there are three styles of control - primary, secondary and relinquished - which will be chosen on the basis of the situation appraisal. While control appraisal has received a great deal of attention in the adult research literature, few studies in the paediatric literature have assessed children's perceptions of control in stressful situations.

Coping responses vary as a function of the individuals cognitive appraisals of his or her relationship with the environment. Situations judged to be within the power of the individual to influence will result in more active coping responses than situations where the individual perceives themself as unable to affect the flow of events (Band and Weisz, 1988). Some researchers suggest that the controllability of a stressor influences the degree to which a child's chosen coping strategy is adaptive (Weisz et al., 1994; Compas, 1987; Peterson, 1989).

A major implication of age/developmental differences in expressions of pain, distress and anxiety relates to assessment. The focus on illness, and illness-related tasks, can dominate all interactions with the child with cancer to such a large extent that the normative, developmentally-relevant tasks for the child are forgotten, even though the child may still be attempting to master them. Behaviours which may assessed as signalling pain, distress, and anxiety, could instead be behaviours related to a normative developmental task. For example, refusal to cooperate with a medical procedure in a ten year old, could be an attempt at achieving autonomy - a developmental task, or an anticipatory distress behaviour.

Therefore, when assessing children's coping responses it becomes vitally important to keep sight of what are commonly viewed as the cognitive abilities and normal behaviours of a child, and how these might relate to the current medical procedures. The child with cancer is, first and foremost, a *child*, whose appraisal of the controllability of the cancer experience will be related to both their developmental level and their cognitive maturity, which in turn influences the availability, and selection of coping strategies. This has implications for the introduction of interventions, which will be discussed later in this chapter.

Parental Influence

In addition to the influences of age and gender, the people who are present during the procedures also influence behavioural responses. The process of cancer diagnosis and treatment has long been considered stressful for parents (Steward, O'Connor, Acredolo and Steward, 1996), and while some parents are able to facilitate their child's coping, others are at a loss. Unfortunately, the trauma for the child is often compounded by parental distress (McGrath and McAlpine, 1993). Manne et al.'s (1992) findings indicate that parents' ratings of their child's distress during procedures, may be an indication of preconceived ideas of what their child will experience, and are little changed through observation of the actual procedure.

Three behaviours that typically precede child distress (crying) were found by Blount et al. (1989), in their study of the relationship between adults' behaviour and child coping/distress during BMAs and LPs. The behaviours were giving control to the child, criticism and apologies. The most common response to child distress (crying) was verbal reassurance, which had a higher probability of preceding further distress than commands to use coping strategies.

The interactions of 51 children with leukemia, their parents, and physicians, were observed during BMA and LP procedures, (Dahlquist, Power, and Carlson, 1995). Interactions were coded using the Child-Adult Medical Procedure Interaction Scale (CAMPIS), which found that more interaction occurred in the procedural as opposed to the anticipatory phase. Furthermore, parents' communications with their children, although more interactive overall than physicians, were nonetheless ineffective in reducing distress. In contrast, physicians, even though they interacted less than parents, were more effective in decreasing distress. The authors also found that the younger the child, then the more the parent interacted with them, and the greater the distress score. This would make sense in light of the previous findings of parental interaction and its effects on distress.

These studies highlight the potential for physicians and parents to positively influence the distress of children during procedures. The findings indicate that formal instruction of parents and medical personnel in stress management techniques, would be effective in eliciting coping behaviours from children, and reducing distress. For parents, this may be facilitated through education in the timing and appropriateness of interactions, while for medical personnel it may involve an increase in the types of interactions currently employed. Interventions of this type may have the added benefit of decreasing parental and staff distress, therefore being beneficial to all parties involved (Jay, et al., 1987; Kuttner, Bowman, and Teasdale, 1988; Blount et al., 1989; Kazak et al., 1996).

There is research evidence which highlights the discrepancy between child self-reports and observer reports (Klein, 1991). Given this discrepancy, and a lack of information on the criteria for judging the accuracy of one source over another, it seems advisable to obtain information from a variety of sources wherever possible, especially the child. Given the likelihood, as presented in the literature above, that both parents and medical personnel view a child's pain and distress from a different perspective it is of use to discuss the importance of self-report data.

The ultimate aim of the body of research reviewed above is to formulate a picture of children's styles of coping, the strategies they choose, and possible factors which influence that choice. This information is needed to develop effective interventions for the management of the pain, distress and anxiety associated with the current treatments for cancer. The following is an examination of the literature focused on interventions and their effectiveness in providing strategies for managing the pain, distress and anxiety associated with painful procedures common to the treatment of paediatric oncology.

Intervention Studies for Behavioural Coping Responses

Interventions in the paediatric oncology literature related to the pain, distress and anxiety resulting from medical procedures, fall into three general categories: hypnosis, cognitive-behavioral, and pharmacological. As with pain, distress and anxiety, there is much haziness surrounding exactly what is meant by hypnosis, (Ellis and Spanos, 1994, provide a good review of the issues), slightly less confusion surrounding cognitive-behavioral interventions, with only pharmacological methods being clear cut.

With the acknowledgement of the widespread underestimation of pain in paediatric populations, interventions have multiplied (Eiser, 1990). However Hockenberry, and Bologna-Vaughan, (1985), in their review of preparatory methods in the area of paediatric oncology procedures, found topical pre-medication used in 87% of BMAs and LPs, sedation used as needed, while non-invasive methods, (such as, hypnosis and cognitive-behavioral interventions), were utilized as part of standard practice in only 14% of institutions reviewed. The authors believe that as treatment often results in regression, developmental delays, and loss of control, noninvasive methods should be used more frequently as they return a degree of control to the child, allowing them to actively participate in their own treatment, while carrying minimal risk.

The efficacy of non-invasive methods has been studied by few researchers in the area of paediatric oncology, although a large body of research exists concerned with children and medical procedures in general. Only those studies directly focussed on paediatric oncology patients are reviewed here.

A study assessing the effectiveness of a hypnotic intervention for 24 children and adolescents with cancer undergoing BMAs, was carried out by Hilgard and LeBaron, (1982). They compared baseline observations, with subsequent observations and self-reports of pain for patients undergoing BMAs. Results found a reduction in self-reported pain for the majority of subjects, while those assessed as less hypnotizable benefited by reducing their anxiety.

A cognitive-behavioral intervention package, a low-risk pharmacologic intervention, and a minimal treatment-attention control condition were assessed for their effectiveness of in the alleviation of distress in 56 paediatric patients with leukemia, in a study by Jay, et al. (1987). The interventions were given in a randomised pattern within a repeated-measures counterbalanced design, so that all participants experienced each of the interventions. Results showed children in the cognitive-behavioral intervention had significantly lower behavioural distress, pain ratings and pulse rates than when in the attention-control group. However, findings also showed that the cognitive-behavioral intervention did not generalise to subsequent BMAs. This is an important point as the aim of interventions is to assist in developing coping responses which will be effective in reducing pain and distress over time, and different situations. It is possible that the effectiveness of the cognitive-behavioral intervention was due more to the presence of a coach, than the actual responses being coached.

Oral Valium (the pharmacologic intervention), failed to demonstrate any significant differences when compared with the minimal treatment-attention control condition, although it did reduce anticipatory anxiety. Interestingly, Valium was highly rated on a 5-point Likert scale as helpful by parents, and even more so by children. This may be due to the dominance of the medical model of health and the over-reliance on, and confidence in, pharmacologic interventions. Overall, parents rated (on a 5-point-Likert scale), the cognitive-behavioral intervention as most helpful, followed by Valium, then the attention control. Children were not asked to rate the helpfulness of the three interventions.

Jay, et al. (1987), agree with Hockenberry, and Bologna-Vaughan (1985), that cognitive-behavioural interventions are of greater benefit than pharmacologic approaches for a cople of reasons. Firstly, cognitive-behavioural interventions benefit the child's sense of control, both behavioural and psychological, and secondly they provide an increased likelihood of positive approaches to future stressors. In saying this it is important that efforts match the actual controllability of the situation, or the effects could negatively impact self-esteem, and perceptions of control. This is supported by Smith et al. (1989), whose study, discussed earlier in relation to coping styles, found that matching behavioral interventions to preferred coping style in children with cancer undergoing BMAs and LPs, resulted in higher self-reports of pain. It was considered that disease chronicity was more salient than preferred coping style. Controllability was perceived to be greater with increased time from diagnosis, and should be considered in the design of interventions, because different interventions may be required at different stages of treatment. The inappropriate introduction of interventions could result in unsuccessful attempts to control pain and anxiety, thereby negatively affecting the child's assessment of the resources at their disposal, their own effectiveness, and the controllability of the situation.

The implications for interventions are highlighted in a study by Kuttner, et al. (1988), which evaluated the relative efficacy of imaginative involvement, behavioural distraction and standard medical practice in the reduction of pain, distress and anxiety in 59 children with leukemia undergoing BMAs. Distraction with younger children was found to require more than one session to effect a change in pain, distress and anxiety, therefore indicating that more than one training session prior to a procedure may result in greater efficacy. In contrast, older children showed a reduction in pain and anxiety after the first intervention as distraction was seen as developmentally appropriate in assisting with the mastery of the developmental task of developing a sense of industry (Erikson, 1963), by managing oneself and taking responsibility for coping with the aversive procedure.

Another example is provided by Kazak et al. (1996) who emphasize the importance of parental involvement, particularly with younger children, where interventions can be designed that maximize the natural interaction between young children and their parents, assisting with the attainment of normative developmental tasks for the child. Evidence of the developmental appropriateness of parental interaction with children, but especially younger children, is provided by Dahlquist et al. (1995), who found that the younger the child the more the parent interacted with them.

An important implication of the research related to efficacy of interventions, is the need to include self-reports as part of the process. These self-report measures require a level of sensitivity to the subjective perception of the child, so that an idea of the coping goal, as formulated by the child, can be ascertained. Interventions, based on studies which do not contain self-reports, may decrease the observers' ratings of observed distress/pain while possibly making no impact on the subjective experience of the child. This is highlighted in Kazak et al. (1996), where mothers' perceptions of their child's distress decreased over time with an active and effective intervention. However, other researchers (for example, Katz et al. 1980, and Jay et al. 1987) have found evidence of non-habituation to stressful procedures, and Manne at al. (1992), found parents and nurses rated children as less distressed if they had more prior experience with venipunctures. One group of researchers, Kellerman, Zeltzer, Ellenberg and Dash (1983), even found an increase in distress with subsequent procedures.

Research with children has typically involved projective techniques, and quantitative tests and scales, which although self-report in style, do not allow expression outside the confines of the options presented. These measures are used as it is widely believed that children lack the ability to effectively communicate their experience, and lack understanding of the assessment task. This assumption regarding children's ability to communicate has "persisted despite increasing clinical and research evidence to the contrary" (Ross and Ross, 1984, p.180). For example, Kazak et al. (1996), did ask patients to rate their own distress but subsequently omitted the data as "the young age of the sample made it difficult to obtain reliable and valid ratings" (p.622). No indication is given of how reliability or validity was assessed, and the use of 'young' is misleading as participants ranged in age from birth to 17 years of age.

An alternative interpretation of the variability among raters has been proposed by Manne at al. (1992): "...rather than concluding that data obtained from certain individuals is invalid, it may be useful to understand the factors that contribute to differences among ratings" (p.46). In their study comparing child self-report, parent ratings, and nurse ratings of pain and distress during venipunctures, they found significant correlations between all possible pairings of measures. These high correlations, however, masked important differences in what the measures represented to the raters. Results of regression analyses found that nurses ratings were *primarily* related to overt behavioural distress; the child self-report results, were *primarily* associated with their age; and parent ratings were *primarily* reflective of their own anxiety, both prior and during the procedure.

Other studies which have utilised self-reports have provided important information necessary for the design and assessment of effective interventions. The results of Katz et al.'s (1987) study, showed both hypnosis and play interventions to be equally effective in decreasing self-reported fear and pain, while observational data showed a rise in distress scores, supporting the need for multiple assessments of children's experience.

Ross and Ross (1984) and Savedra, Gibbons, Tesler, Ward and Wegner (1982) uncovered evidence of children's ability to describe factors that would help them in painful situations, these included pharmacological and psychological, self-generated and other-generated responses. For example, the flexible visiting hours on paediatric wards, and the accommodation of parents with their children are interventions based on children's statement that the presence of a parent helped in painful situations (Ross and Ross, 1984; Savedra et al., 1982; Woodgate and Kristjanson, 1996). Also, Jay et al. (1987) assessed the distress associated with BMAs, asking children which of the five treatment components "helped the most" and which they "liked the most". Results showed that children were "clearly able to distinguish between what was most helpful and what was most likeable"(p.863).

The ability of children to communicate their feelings has implications for interactions with medical personnel, as doctors, in particular, have been found to treat children of varying ages in the same manner (Perrin and Perrin, 1983, cited in Harbeck-Weber and

McKee, 1995), not accounting for differences in language, cognitive and developmental level. Appropriate wording of information, and allowing children the opportunity to ask questions and seek clarification, aids in the empowerment of the child.

The literature on interventions makes several points. Firstly, pharmacological methods are widely perceived as helpful, even though their efficacy may be moderate. Secondly, interventions may not be as effective for children of all ages, with behavioural interventions working better with younger children than more cognitive methods. Thirdly, some interventions may require a longer induction period before children can initiate the coping responses without coaching. Fourthly, interventions may need to take account of the time since diagnosis of the child, as this may influence the use of various coping strategies. Finally, the design of interventions, and the assessment of their efficacy, will be greatly improved with the use of self-report measures which allow for subjective perceptions to be expressed.

The following group of studies is a sample of those which assess the coping outcomes of paediatric oncology patients, through the measurement of adjustment.

PSYCHOLOGICAL ADJUSTMENT

The literature within this area examines psychological adjustment as indirect evidence for the efficacy of children's coping. The range of issues covered, and the relative paucity of studies makes drawing anything other than tentative ideas of the effectiveness of children's coping impossible. Furthermore, the majority of research reviewed below focuses on the measurement of maladjustment, for example, the presence of depressive symptoms, rather than providing information on the behaviours and attitudes which are conducive to, and indicative of, adjustment.

Adjustment to the cancer experience is assessed through the presence or absence of symptoms or behaviours indicative of psychological disturbance. "Although there is a growing consensus that chronically ill children and their families do not evidence "psychopathology" per se...recent surveys suggest that these children are at increased risk for behavioural and emotional problems" (Quittner, 1992, p.85).

Family Functioning

The impact of cancer on the child's perception of the family was examined using the Kinetic Family Drawings-Revised (KFD-R; Bossert and Martinson, 1990). Scores of communication, self-image, and emotional tone increased over time, representing an increasingly negative perception of self, and family interaction. Differences in trends were found between children with leukemia and solid tumours, with children with leukemia perceiving the family more negatively. Differences were also found between those who had relapsed versus those in remission, with the latter having lower scores, but increasing more over time than those who relapsed.

These results may relate to the changes in family functioning as a reflection of disease chronicity, and emphasizes the importance of considering the unique demands of the various phases of diagnosis and treatment. It also highlights that while medical treatment has made great gains, the need to maintain the holistic health of the individual is vital if 'true' survival is to occur.

One study of the quality of survival investigated the incidence and severity of Post-traumatic Stress Disorder (PTSD) in paediatric oncology patients, (Butler, Rizzi and Handwerger, 1996). A full range of PTSD symptoms were observed, but these were no more than estimates of presence in the general population. Factors significantly related to the presence of PTSD symptoms were: being on treatment at the time of the evaluation, being in the preparatory phase of a bone marrow transplant and not having received cranial radiation. Further findings were that decreased family cohesiveness was predictive of PTSD symptoms, and that PTSD symptoms co-exist with socialization difficulties in children. This suggests that medical trauma may not create greater risk for PTSD, if adequate emotional support and social skills are available. Foa, Zinbarg, and Rothbaum (1992), theorized that PTSD is more likely to result from stress that is uncontrollable and unpredictable. If this is the case then the chronic nature of cancer, and the schedule of treatment may be less likely to cause PTSD.

Depression

Several investigations have been conducted into the presence of depression in children with cancer, all of which have found lower levels of depression in this group compared with normative samples. Worchel et al. (1988), compared scores on the CDI, of children with cancer, normal children and inpatients in a child and adolescent psychiatric hospital. Results showed that children with cancer reported less depression than the other two groups. It is suggested by the authors that children with cancer may be using denial as a coping mechanism. However this suggestion is weakened by the researchers' observations that children with cancer expressed anger, anxiety and depression in private with people they were comfortable with, for example, parents. It may be that children with cancer learn when, where and with whom it is appropriate to share their feelings.

The authors propose that the CDI is a poor indicator of depression in children with cancer as many items index somatic symptoms common to the cancer experience, for example, tiredness. Furthermore, many of the cognitive items were related to low self-concept which is considered fairly common in paediatric cancer patients. Given these points it would appear even more surprising that children with cancer score lower than other populations.

Lower scores on the CDI for children with cancer, compared to a normative sample, were also found by Canning et al. (1992). The researchers went on to assign children to a either a repressive or a sensitizer (i.e. avoidant versus approach), coping style, finding a significantly higher number of repressors among the cancer patients, and among girls. The use of a repressive style may account for the lower scores of depressive symptoms.

Repressive style is unlike denial in that it is associated with self-deception (Weinberger, 1990), and different to being unwilling to share one's feelings (Worchel et al., 1988). Differences in the effectiveness of a repressive style of coping may be related to time so that in the short term it may be adaptive, but continued use over time may negatively impact the individual's health as they can become more defensive and less able to assess their situation and act with accuracy. It is difficult to assess that adaptiveness of repressive style in the current study as no analysis of disease chronicity and repressive style is reported.

Suggestions of a halo effect have been made by Kaplan, Busner, Weinhold and Lenon (1987) to explain their findings of low rates of self-reported depression in children and adolescents with cancer. The halo effect is thought to be a response to a demand expectation in the social environments of cancer patients to minimize complaining. This is related to the idea mentioned in Chapter One of the child as protector, that is, in order to minimise the distress of those involved in their care, they learn to mask their depressive symptoms. An alternative explanation is that depressive symptoms are improved through the increased level of support provided to children.

In addition to assessing self-reported depression, Kaplan et al. (1987), studied psycho-social life events, such as failing a subject at school, and depression. They found higher levels of depression in participants who reported a greater number of negative psycho-social life events. This highlights the need for psycho-social interventions, for if depressive symptoms are not solely a result of medical events, but related to the everyday concerns of children and adolescents, they are able to be positively influenced through early intervention.

The prevalence of emotional and behavioural problems in children with cancer was assessed by Sawyer et al. (1995). Assessment was carried out immediately after diagnosis and at a one year interval, using the CBCL, and a youth self-report scale. Results showed younger children post-diagnosis to experience more internalising problems than the general population. However, at one year, the difference was largely gone. This can be explained by the greater distress experienced by children in the early stages due to separation from parents, hospitalisation, and difficulty understanding the reasons for treatments. Older children were not found to show any significant differences to the general population.

These studies on the incidence and prevalence of emotional and behavioural difficulties indicate that children with cancer are not notably different to the general population. In fact, children with cancer show lower levels of depression than would be expected. Many reasons have been suggested for these findings, and all of which could be correct. Firstly, three of the studies used the CDI, which may be a poor indicator of depression in children with cancer as the measure contains several physical items which are common in this population. Secondly, a repressive coping style may be in use, while a third suggestion is that findings result from a halo effect. A fourth explanation relates to the possible role of adequate social support and social skills in reducing depressive symptoms. A fifth possibility is the timing of assessment as older children and children at a greater distance from diagnosis exhibit no more emotional and behavioural difficulties than the general population. Here again, the use of self-report measures allowing the expression of subjective perceptions, as part of the assessment process, would greatly assist understanding.

Body Image

Two studies were found that examined the perception of body image. In children with cancer there are obvious physical signs of illness and its treatment, for example hair loss, that may alter the ways in which people respond to them, causing the child to feel different. Children therefore require the opportunity to explore their concerns about the future and how to handle social activities and others responses to them. There is a uniqueness to living with cancer that can affect a child's self-concept formation, and physical appearance plays a large role, in Western society, in the development of one's self-image.

The possible role of perceived physical appearance as a predictor of depressive symptoms, social anxiety, and general self-esteem in newly diagnosed patients with cancer, was investigated by Varni, Katz, Colegrove and Dolgin (1995). A positive perception of physical appearance was found to be associated with lower depressive symptoms, lower social anxiety and higher general self-esteem. Physical appearance was found to predict general self-esteem, which in turn predicted depressive and anxious symptoms, while perceived competence/adequacy, in combination with perceived physical experience increased the perception of general self-esteem. These findings suggest that the effects of perceived physical appearance on depressive and anxious symptoms can be reduced by interventions designed to increase general self-esteem, namely through perceptions of perceived competence/adequacy (defined in terms of social acceptance, scholastic competence, and athletic competence). For example, Varni, Katz, Colegrove and Dolgin (1993), found children with newly diagnosed cancer who received social skills training perceived higher teacher and peer support, which significantly predicted higher general self-esteem and lower depressive and anxious symptoms. It is difficult to determine the direction of effect - does perceived physical appearance predict psychological distress or vice versa? It may also be important to educate children to differentiate between bodily changes which are normative and those which are due to treatment so as to normalise some body concerns which may be common to all children.

Body knowledge may also differ between children with cancer and the general population. Neff and Beardslee (1990), investigated the possible differences in body-related knowledge and concerns of: children with cancer, children with a chronic or acute orthopedic condition, and a normative sample. Results found children with cancer to have better knowledge of body functions, suggested to be due to cumulative experience with illness and hospitalisation, though overall, children's knowledge was poor. Concern about body boundaries was more apparent in the cancer group, this is understandable as they have probably experienced the least amount of control over their situation in comparison to the other two groups. Older children had more concern about threat to body integrity, with children in the cancer group endorsing more items. Concern about body boundaries and body integrity were still lower than expected, perhaps because concerns are thought to be greater when directly faced with a threat, such as a lumbar puncture.

Body knowledge and body concerns are formed in certain situations, but can also be the result of interaction with others, particularly perceived physical appearance. The development of a positive self-concept in children with cancer, can be influenced by other peoples reactions to them. These reactions may be made in response to a number of factors, such as physical appearance, or deficits in social skills. The main context where the child with cancer must cope with the reactions of others, is school. School represents the workplace of childhood, and is the major context within which ongoing socialization and social support operate. The school years are also the time where the development of positive peer relations is important.

Self-Esteem

Children with newly diagnosed cancer experience illness-imposed limitations and extensive medical treatments, which physically isolate them, but also create isolation due to the uniqueness of their experiences. Both of these factors can create a disruption in the child's social relations with classmates and teachers, where a diminution of perceived classmate and teacher social support might be expected. The following three studies examined the influence of perceived social support and acceptance on self-esteem and levels of anxiety.

Measures of depressive symptoms, state anxiety, trait anxiety, general self-esteem, and perceived social support were obtained from classmates, parents, teachers and friends in a study by Varni et al. (1994). Higher perceptions of classmate, parent and teacher social support were found to be associated with lower psychological distress and higher self-esteem. Perceived classmate support was the most consistent predictor of adjustment, associated with lower depressive symptoms, lower state, trait and social anxiety, higher general self-esteem and lower behaviour problems. Older children reported less depressive symptoms, but higher trait anxiety, and more internalizing and externalizing behaviour problems. Gender trends showed girls demonstrated lower externalizing behaviour problems, higher perceived social support and higher perceived friend social support.

In another study utilising both peer and self-ratings, Noll, LeRoy, Bukowski, Rogosch and Kulkarni (1991) evaluated the adaptation of children with cancer, compared to a classroom control on dimensions of social reputation, interpersonal acceptance, self-worth, and loneliness. Results showed that although peers rated them as more sensitive and socially isolated, no parallel findings appeared on measures of acceptance by peers. Children with cancer did not report a poorer self-concept, or greater loneliness, than the normative sample. These results support the above findings of Varni et al. (1994), of the importance of acceptance by peers for the development of general self-esteem.

The relationship between cancer stressors, protective factors, and physiological and psychological responses during treatment, was explored by Hockenberry-Eaton, Kemp and DiIorio (1994). A protective factor is defined as any attribute of the child, family or situation which alters the perception of the target stressors, so that the stress is reduced. Perceived support from friends was related to a low physiological response (measured by levels of norepinephrine, epinephrine, and cortisol present in urine samples), while perceived social support from teachers, family activities and recreation, and family cultural/intellectual orientation was associated with low levels of state anxiety.

Findings of the beneficial impact of perceived social support on measures of self-esteem, loneliness and anxiety, reinforce the suggestion of social support as a protective factor in the experience of cancer stressors. The importance of the school context is also highlighted as the majority of social support originates in the school environment.

Communication

The remaining four studies are concerned with the influence of communication and disclosure on children's psychological adjustment. As stated in Chapter One, communication is vital to minimise the chances of children creating their own story for what is happening, in the absence of accurate information. Furthermore, communication is the means by which children share their fears, anxieties, hopes and wishes with those who are important in their lives.

Hardy, Armstrong, Routh, Albrecht and Davis (1994), investigated the patterns of communication between parents and their ill children. Parents of children with cancer were more likely to have told their child of the diagnosis, than the parents of children with HIV. These findings have implications for coping, and relate to the issue of open communication and disclosure. In previous studies of communication within paediatric populations, researchers found that children were aware of their illness and impending death despite their parents' stance of protective communication (Bluebond-Langner, 1978; Waechter, 1971). The withholding of information can negatively impact trust between children and their parents and medical staff, while also making it difficult for children to know who they can talk to honestly about their situation.

The amount of disclosure may be related to age of the child, but as the cancer diagnosis and treatment process is frightening, a lack of information may exacerbate the situation. Claflin and Barbarin (1991), examined information from 43 children with cancer about their diagnosis disclosure, causal attributions, illness-related stress and coping strategies. Results showed that younger children reported being told less than children aged 9 years and over. This may be due to a lack of memory, or repression, although these explanations are unlikely in view of evidence of children's recall of other events. Even though younger children were told less, their levels of distress were comparable to those of older children who were told more. This indicates that non-disclosure for protective reasons may be ineffective, as there may be contextual information that the child is absorbing, such as the distress of parents. Non-disclosure may be as much for the parents' benefit as the child, as parents may be so distressed that they are unable to talk with their child. Finally, younger children report wondering why they became ill as frequently as older children.

Interestingly, Hockenberry-Eaton, Kemp and DiIorio (1994), found that one of the factors which explained increased physiologic responses to stressors was family expressiveness - defined as being open and communicative. This may be accounted for by open discussion of difficulties, such as financial strife, which are a consequence of the cancer experience, but may increase the child's anxiety. Again, this is possible evidence for the role of the child with cancer as 'protector', feeling responsible for the stability of the family.

A card sort game was utilised in a study comparing the information needs of adolescents with cancer with the perception of physicians, (Hooker, 1997). Results showed that teenagers' top three priorities were information about their diagnosis, prognosis, and treatment. These were also rated as the top priorities for the physicians. The remaining priorities for teenagers related to how their treatments worked, general information about cancer, and how cancer might affect them in the future. These were not ranked as highly by physicians who overestimated the importance of psychosocial issues such as, appearance, who the young person is able to talk to, and relationships. It is difficult to deduce whether these latter issues were of less importance or whether adolescents had gained this information from the environment.

The most comprehensive study of the various aspects of the cancer experience for young people, was conducted by Eiser, Havermans, Craft and Kernahan (1995), who developed a measure to assess the perceived illness experience (PIE). Semi-structured interviews generated nine areas central to the cancer experience: physical appearance, interference with activity, peer rejection, integration in school, manipulation, parental behaviour, disclosure, preoccupation with illness, and impact of treatment. From this information, 34 statements were derived and put together to create a scale. Scoring was on a 5-point from disagree to agree. The scale was then trialed with 41 patients. Results showed that a high score on the physical symptoms sub-scale was related to a high total PIE score, and high scores on the sub-scales of physical appearance, and interference with activity. These findings indicate a greater impact of the illness generally, and specifically on perceptions of body image and activity. Children who reported restrictions in carrying out daily activities, reported more interference with activity and difficulties with parental behaviour. Also, children who reported more psychological symptoms, reported a more negative impact of the illness on the sub-scales physical appearance, interference with activity, and manipulation.

Younger children rated the impact of their illness on physical appearance less than older children, and those who had completed treatment reported a greater impact on school integration than those on maintenance treatment. This is expected as research has highlighted delayed achievements and educational disadvantage among long term survivors (Madan-Swain and Brown, 1991), and while teachers and parents may make allowances during treatment, concerns for future academic success and employment become more important after treatment. That is, while the fight for life is on, academic concerns are negligible, and only come into their own once survival is assured. Parent and child ratings did not correlate on the overall PIE score or on the sub-scales of disclosure and impact of treatment, but were significant on all other sub-scales. This re-emphasises the point made earlier regarding the importance of self-reports. The discrepancy between parents and children on the total PIE score, indicates that parents to perceive the illness experience in the same light as the children. It is also of interest that the two sub-scales which influence the overall correlation, information disclosure and the impact of treatment, are areas not readily discernible to the observer, instead requiring shared communication for accurate assessment.

The studies on communication, and the study of Eiser et al. (1995), assessing the impact of the illness experience make two important points. Firstly, non-disclosure of information does not necessarily result in the reduction of distress, in fact it may exacerbate the child's sense of isolation. Secondly, children's information needs, and assessments of illness impact do not totally match those of observers. These studies indicate the need to fully understand the nature and extent of problems experienced by children as they progress **through** their treatment, and recovery from cancer, rather than trying to deal with them after the damage has been done. To fully appreciate the children's experiences requires a recognition of the disparity between self-reports and other-reports, and a greater willingness to communicate with the children about those experiences. The new measure designed by Eiser et al. (1995), provides a good starting point.

CONCEPTUAL AND METHODOLOGICAL ISSUES

The research area of coping in paediatric oncology patients contains several conceptual and methodological challenges. The conceptual difficulties relate to a lack of definition of commonly used terms, and a wide range of approaches to the study of coping. Many of the methodological challenges result from constraints inherent in the nature of cancer, and its treatments.

There are several conceptual points needing consideration if our understanding of coping in children with cancer is to improve. Firstly, coping as a term requires delineation. Is a child said to be coping when they initiate coping responses, or when coping outcomes are measured? How are spontaneous reactions differentiated from coping responses? What is coping measuring? The current research literature is rife with inconsistencies in the defining and operationalising of the elements of the coping process being studied. The central difficulty lies in the lack of delineation between what represents a coping style, strategy or outcome. Secondly, a conceptual challenge is present in the wide range of distinctions, outlined earlier, regarding coping style (for example, problem-focused Vs emotion-focused). This range creates difficulties in the development of a solid base of knowledge as comparison across studies is troublesome.

Thirdly, current coping assessment methodology fails to indicate the complexity of children's coping, (Weisz et al. 1994). This is partly due to the focus on the medical model of health with its emphasis on illness, and psychopathology (WHO, 1978; Eiser, 1993). This focus turns the assessment process into a search for indications of ineffective coping responses, while missing the observation of naturally occurring behaviours which, if encouraged, could assist in the coping process. Blount et al. (1989), make the pertinent point that "most scales in the area of paediatric pain focus only on child distress, ignoring child coping behaviors and other routine behaviors that the child engages in" (p.586). This relates to the point made earlier, namely that behaviours may be more indicative of developmental stage and self-expression, than any real indication of distress, anxiety or pain.

Assessment methodology is further limited by the lack of consideration of the coping goals as defined by the child. As stated earlier in this chapter, coping goals may differ between child, parent, and medical personnel. Differential goals result in differential interpretations of the purpose and efficacy of coping responses. Both concern with the medical focus of assessment, and the need to examine children's coping goals, would be addressed to a large extent with the use of self-report measures, and semi-structured interviews.

The majority of methodological challenges are inherent in the area of study itself, however, there is one central issue which is not. This issue, related to the conceptual challenge of definition, involves the need to define what is captured by the measures used. Throughout the research literature there is the interchangeable use of the terms distress, anxiety and pain, and therefore a lack of clarity regarding the purpose of assessment scales and measures. Observed behaviour scales (e.g., The Procedure Behavior Rating Scale Revised (PBRS-R), and The Observational Scale of Behavioral Distress (OSBD)), were utilized to rate children's distress, anxiety and pain in reaction to procedures with no breakdown as to the contribution of each behaviour to the overall score.

This creates difficulty in reaching clear conclusions. For example, Manne at al. (1992), recognize that the scale they utilised may have combined perceptions of pain with fear and distress. Their finding that "age was the best predictor of self-reported pain and distress may actually indicate that the child's fear and distress decreases with age, not that pain experienced decreases with age" (p.50). This lack of construct definition also creates difficulty when designing interventions, as a behaviour labeled as indicative of distress and treated with distraction, may in fact represent pain and be best dealt with pharmacologically. The implicit belief that distress, anxiety and pain are essentially the same thing, and can be measured with the same instrument appears to need challenging.

The remaining methodological difficulties for researchers in this area relate to situational constraints, and result in a lack of generalisability of findings. The first challenge is obtaining sufficient numbers of participants for study. Although cancer is the second most common cause of death in children in the Western world, the numbers affected are relatively small, evidenced by the low numbers in most of the studies reviewed. A second pattern in the literature is the reliance on children with leukemia as they form the largest group, and therefore treatment effects can be controlled. This is a limiting factor as children with tumours have been found to cope differently both in terms of responses to stressors, and outcome. These may result from the differences in their treatment protocols, and is an important factor to investigate. Thirdly, studies have relied on participants from a single treatment setting, where the assessment of coping responses and outcomes may reflect the interaction between environmental factors such as personnel or preparatory methods, and the individual. Finally, coping studies have focussed on those medical procedures in which observations are more readily made, such as BMAs and LPs. There are other aspects to the cancer experience which are equally, if not more distressing, such as chemotherapy and radiation therapy. The demands of these stressors are diverse and may require the design of alternate assessment measures, and interventions.

There is much still to be learned about the coping of children with cancer, and as outlined above, many difficulties to deal with. The research to date, has provided an important start on our journey towards greater understanding, and has raised some valuable points that require consideration in the development of future research in this area.

CHAPTER THREE

INTERPRETIVE PHENOMENOLOGY

In conducting any piece of research there are several questions which require answering. These questions relate to the assumptions of the researcher in addition to the goal of the project which, in the current study, was to elicit the hospitalisation experiences of children with cancer. In addition, they also query the methodology being used and why it is particularly suited to answering the research question. The questions can be seen to refer to five differing, but related dimensions of the research process: ontology, epistemology, theoretical perspective, methodology and method; each of these informs, and is informed by the others (Crotty, 1998). These five dimensions are not on an equal plane, placed side by side, but rather form a hierarchy of influence whereby lower levels form the foundation of those above; this can be likened to a scaffold.

The current chapter deals with the four lower levels of the scaffold, namely ontology, epistemology, theoretical perspective and methodology. The uppermost level, method, is that part of the research process most accessible to research consumers. Method describes the physical activities of the research project. The next level down, methodology, informs method and refers to the rationale linking the research question with the chosen method. Theoretical perspective forms the next level down and deals with the assumptions the researcher holds about the world and its existence, which inform the choice of methodology, and thus method.

At the lower levels of the scaffold are epistemology and ontology. Epistemology concerns itself with the shape, size, texture and boundaries of 'knowledge'. It is the frame within which the research is confined. Ontology is closely tied to epistemology, but while epistemology provides the frame for 'knowledge', ontology dictates what it is possible to view within the frame, that is, what is accepted as 'knowledge', and its nature and structure. Theoretical perspective, epistemology and ontology are more difficult to discern in the research process, and, even for the researcher, difficult to explicate. But the declaration of one's ontology, epistemology, and theoretical perspective forms a vital part of the research process, providing the consumer with a basis for critique and evaluation of the study.

My understanding of ontology, epistemology, theoretical perspective, methodology and method has, to a large extent, been gained from the writings of Crotty (1998) and van Manen (1990). The following descriptions of the various levels of the scaffold for the present study owe much to the influence of their writing. Each level will be examined in turn, beginning with the grounded lower levels of the scaffold and moving up to reveal the more flexible structures which are supported by the lower levels.

ONTOLOGY

The ontology of this research is that of realism. Realism, in contrast to idealism which sees reality as created by our cognitive activities, asserts that there is a reality which exists outside of the mind, that is, that a tree exists whether or not I see or think of that tree. For example, the current study takes as given the existence of cancer as a serious disease. Cancer does not require that we acknowledge its presence, it continues to function regardless. In the same way, treatments for cancer have side-effects, these will occur whether we choose to notice them, or not. A non-physical example is that of the hospital experiences of children with cancer. Children with cancer spend time in hospital and develop an acquaintance with people and events particular to that environment; knowledge ensuing from this acquaintance represents their experiences. These experiences, just like cancer and the side-effects of its treatment, exist and function whether they are acknowledged by others, or not.

Realism does not see humans as necessary for the world to exist. This does not imply, however, that the world has meaning, merely that it exists independent of human consciousness. In the same way, although cancer, side-effects of its treatment and children's experiences exist, they are without meaning if they remain unacknowledged, and therefore unexamined.

EPISTEMOLOGY

What then brings meaning to the world?

> "..what kind of world is there before conscious beings engage with it? Not an intelligent world…not a world of meaning. It becomes a world of meaning only when meaning-making beings make sense of it." (Crotty, 1998, p.10)

This brings us to our epistemology, which in this study is that of constructionism. This frame sees knowledge as constructed within a social context, through an interactional process where each person is both teacher and student, knower and known. Meaning is not an inherent part of reality, but is 'made'; human knowledge is thus interpersonal and constantly evolving (Neimeyer, 1993). Constructionism has as a central assumption the existence of humans as beings who are: conscious, intentional and contextually based. That is, as Crotty states, constructionism involves "the existential concept of humans as beings-in-the-world and the phenomenological concept of intentionality" (1998, p.43).

People are thus seen as free agents able to influence the objects said by realists to be already in existence, and the content of the world in which we live. While people are seen as individuals capable of influencing their destiny, this is not the same as stating that the individual influences the world in isolation. It is important to recognise the social nature of human existence, and with this recognition comes an awareness that meaning-making occurs within a social milieu. This social aspect of meaning is expressed in social constructionism, and the concept of culture. Culture refers to meaning creating by other beings-in-the-world, and which we inherit by our entry into a particular social environment. In the current study this equates to the world of 'being a child with cancer in the hospital'. The meanings already operating in this environment were created by prior beings-in-the-world through their recognition, acceptance and sharing of the naming of a 'new' whole. Not only was a name given but associated definitions of the utility, purpose, and limitations of that environment were also created.

> "When her parents told her she had cancer, Janine began to cry. Her doctor asked , "Do you know what cancer is?" and Janine tearfully shook her head no. Janine was only eight years old at the

> time, but she had already captured the fear that most of us know at the word *cancer*. Yet like many others, adults and children alike, Janine knew little more about the disease than that it was something terrible and scary" (Bain, 1995, p.1).

This extract highlights the fact that none of us can claim to be culture-free. We are all born into a world laden with names, and at our birth we are totally sheathed in a 'mantle of meaning', so that our impressions of the world from our first breath, (some might argue from the womb), are not pure, but rather influenced by the colour, texture, size, and shape of the 'meaning mantle' (culture), we wear. This is not, of necessity, a bad thing. "It is …not the case that individuals encounter phenomena in the world and make sense of them one by one….we depend on culture to direct our behaviour and organise our experience" (Crotty, 1998, pp.53-4), making, of a seemingly limitless number of objects, a meaningful whole. Culture saves us from reinventing meaning for all objects we come into contact with, but it also results in our seeing, touching, tasting, hearing and feeling the world through the fabric of our 'meaning mantle'. This is important to consider when asking for the hospital experiences of children with cancer which are a result of both by the views they bring to the situation, and those inherent in the environment itself. This is also true of the researcher requesting accounts of the hospital experiences of children with cancer in hospital, which will be discussed later in this chapter.

Our view-of-the-world is structured then, by both our meaning mantle, and the characteristics of the object we wish to influence, and it is thus that the process of meaning-making is interactional between subject and object, and of necessity intentional. The intentionality of meaning-making implicit within constructionism is seen when we consider that in order to construct a 'reality', objects are required. The possibilities and limits of objects are explored, and accounted for, in the envisaging and creation of a meaningful reality. The range of possible influence is not, however, unlimited - a doctor, who the child associates with pain, cannot be made to disappear.

Consider the constructionist as working in a spare parts factory: all the objects were at some time part of a whole. The role of the constructionist is to envision a new use for the parts in order to create a 'new' whole. This relates to Lévi-Strauss' concept of the *bricoleur* who has the:

> "ability to 'revision' these bits and pieces, casting aside the purposes which they once bore and for which they were once designed and divining very different purposes that they may now serve in new settings...Research in constructivist vein, ...requires that we not remain straitjacketed by the conventional meanings we have been taught to associate with the object" (Crotty, 1998, p.51).

Straitjacketing occurs when the meaning mantle, from within which we view the world, has grown tight and restrictive. The mantle has not grown with our increased participation with, and exposure to, objects in the world so that it now constrains our ability to move - to conceive of new possibilities, to create new 'wholes'. The removal of the mantle is equivalent to removing, for a brief time, a favourite shirt so that the seams can be let out, and the holes patched. In the absence of the mantle we have the opportunity, in our nudity (of meanings), to experience the world firsthand, in its rawness. Subsequently we may choose to alter our mantle by incorporating newly found meanings.

What is lost, and what is gained, in the filtering of experience through the meaning mantle? Culture serves to reinforce the idea of humans as both individuals and meaning-makers, and with reference to individuals as *bricoleur,* we are able to understand how different people may come to create different realities from the same 'spare parts'. The resultant view-of-the-world is neither 'right' nor 'wrong', but there may be those that are 'liberating' as opposed to 'oppressive', those that are 'useful' as opposed to those that seem to serve no purpose (Crotty, 1998). In the earlier quote regarding Janine, it is possible to see how her view-of-the-world in relation to cancer was oppressive, and served no obvious purpose.

Another example is 'Tommy' who arrives at the hospital for his last chemotherapy treatment. 'Tommy' is a *bricoleur* who has at his disposal the 'spare parts' of doctor, nurse, hospital bed, room, needles, leukemia, pain, nausea, fatigue, boredom, parents, siblings, friends, food, video, television and books. Tommy's experience depends on both his assessment of the characteristics of the 'spare parts', and on the way in which he combines them. Should he envision the 'spare parts' as hurtful and restricting then it is likely that his experience (that is, his 'whole'), will be oppressive. If, in contrast, 'Tommy' sees the 'spare parts' as caring, challenging and necessary, his experience becomes useful to the process of getting better.

THEORETICAL PERSPECTIVE

This brings us to the theoretical perspective for the current study: interpretivism, more specifically phenomenology. The aim of this perspective is to throw off the cultural 'meaning mantle', for a brief period, and see with eyes, touch with skin, taste with tongue, smell with nose, hear with ears, and feel emotions unfettered by layers of subscribed meaning. The meaning mantle is sent to the tailor and we attempt to see the world 'new', without the dividing barrier of given meanings. In the current study, this translates to putting to one side the cultural meanings of children with cancer in hospital, which may involve ideas of negative outcome, pain and suffering. The accounts of the children can then be approached with an open mind, capable of entertaining alternative meanings.

Interpretivism, in contrast to positivism, "attempts to understand and explain human and social reality [by looking]...for *culturally derived and historically situated interpretations of the social life world*" (Crotty, 1998, p.67). One of the possible interpretivist approaches is that of phenomenology. Phenomenology attempts to see the objects in the world in the rawness of their possibilities, without their names and associated layers of meaning dictating our interaction with those objects. Phenomenology compels us to relate our direct experiences with "the objects of our experience before we start thinking about them, interpreting them or attributing any meaning to them...[for] these are the *things themselves*" (Crotty, 1998, p.79).

Inherent in this approach to research is the previously stated belief that culture is both help and hindrance, enabling us to act in the world, while simultaneously confining the ways in which we act, and with what. Phenomenology then, entails taking an objective view of a phenomenon, highlighting the taken-for-granted understandings at work, and questioning their validity. The objectivity of phenomenology may appear to be counter-intuitive when we consider the use of subjective individual's experiences - however, it is through the personal accounts of individuals that cultural understandings are borne out, and can be challenged.

We ask our central question: "What is it like to be a child, with cancer, in hospital?" From the resultant experiences shared with the researcher, we ask: "Is there something essential to the experience of being a child with cancer in hospital?" "How is this an example of a child with cancer's hospital experience?" "Is this what it means for the children?" "Is this what it is like for a child to have cancer and be in hospital?" We are looking for the boundaries within which the individual views: childhood, cancer, and hospitals, and the ways in which they act in relation to their views.

We are also exploring the assumptions which are seen to be inherent in these 'names': child, cancer, hospital. "Phenomenological thinking is a way of working towards seeing that which is essentially there but which labels and symbols often keep hidden" (Walton and Madjar, 1999, p.9). We are undertaking a deep sea dive beneath the surface of the assumed shared meanings of classifications to rediscover what's 'at the bottom' of an experience, to go back 'to the things themselves'. This dive is necessary because "sometimes ordinary words have become too ordinary; we feel the need to get at what is unique, personal, singular, untranslatable about that which we name" (van Manen, 1999, p.17). This way of approaching experiences recognises the centrality of language to the way in which we think and act in the world, and that the effect of language also means that "the meanings we bring to the surface from the depths of life's oceans have already lost the natural quiver of their undisturbed existence" (van Manen, 1990, p.54).

METHODOLOGY: PHENOMENOLOGY

In order to conduct phenomenological research one must be willing from the outset, to abandon ones mantle of meaning (probably positivist in nature), and engage in research with senses aware and open. There appears to be no standard map to this territory, and indeed the creation of such a map would appear impossible as the landscape shifts constantly. (There have been times when I have grasped a clear understanding of what I am doing, only to have it melt like snowflakes in my hand.) The uncertainty of the landscape is well described by van Manen (1990, p.29):

> "The methodology of phenomenology is such that it posits an approach that aims at being presuppositionless: in other words,...tries to ward off any tendency toward constructing a predetermined set of fixed procedures, techniques and concepts that would rule-govern the research project...Heidegger talked about phenomenological reflection as following certain paths, " woodpaths", towards a "clearing" where something could be shown, revealed, or clarified in its essential nature. However, the paths (methods) cannot be determined by fixed signposts. They need to be discovered or invented as a response to the question at hand."

In this study I have chosen to adopt van Manen's guidelines (1990) to the six research activities one should be engaged in. These activities do not comprise a progressive order, but are continuously involved throughout the research endeavour. The six activities are:

1) Turning to a phenomenon which seriously interests us and commits us to the world.
2) Investigating the experience as we live it rather than as we conceptualize it.
3) Reflecting on the essential themes which characterize the phenomenon.
4) Describing the phenomenon through the art of writing and rewriting.
5) Maintaining a strong and oriented relation to the phenomenon.
6) Balancing the research context by considering parts and whole.

It is the first two of these which relate to methodology and are discussed below, the remaining four will be addressed in Chapter Four.

1) Turning to a phenomenon which seriously interests us and commits us to the world. This study began with my deep interest in, and involvement with, children with cancer. Over the years I have spent time with children who were in hospital, for often extended periods of time. The ability of parents and family to be present during these times varied, as did the communication with friends and school. A research question arose from this interest: "What is it like, for a child with cancer, to be in hospital?" This question led to consideration of what it was that I wished to explore - children's experiences - and the most relevant method to employ. A qualitative approach, as opposed to a quantitative approach, was deemed more appropriate as qualitative research approaches are "focussed more holistically, value experience, and seek understanding which incorporates social context" (Chamberlain, Stephens and Lyons, 1997, p.695).

2) Investigating the experience as we live it rather than as we conceptualize it. The focus on experiences means being interested in the ways in which people are as beings-in-the-world. What is the nature of this interest? Is it interest without purpose? No, it is interest in the sense of a desire "to be or stand in the midst of something" (van Manen, 1990, p.43), not to simply allow impressions to wash over us indiscriminately, but to discern the essential structures and present a possible interpretation of the hospital experience of the child with cancer. The interest is tied to the value the interpretation holds in presenting a *possible* human experience, in pointing to some essential element related to *human* experience. The aim, ultimately, is to influence practice through a deeper or increased understanding, or an awareness of previously unconsidered alternatives of viewing an experience.

The Relationship between Researcher and Researched

Qualitative research evolved as a response to the rationalist/empiricist tradition with its emphasis on objective study designed to uncover universal 'facts' or 'truths'. In phenomenology, experience is valued and *accounts* are treated as 'facts' or 'truths'. This frees the researcher to attend to the account, and the participant to give the account without concern for possible contradictions, or for obtaining/providing verification in any form. The open acceptance of expressions of experience also aids in the formation of trust between researcher and participant providing an atmosphere of respect and equality, where the participant is given the status of 'expert'.

It is at this point that the researcher is required to doff their 'meaning mantle', and enter the interview with senses clear and open. The researcher is required to maintain both a demeanor of objectivity and subjectivity - objectivity "means ...remain[ing] *true to the object*. "Subjectivity" means ...to be as perceptive, insightful, and discerning as ...can be in order to show or disclose the object in its full richness and its greatest depth" (van Manen, 1990, p.20).

A consequence of any research endeavour, (acknowledged or not), is that through interaction with the participants, the researcher influences the outcome. In phenomenology, by requesting an account of a phenomenon we alter the individual's experience of it. In asking for a child with cancer's experiences of hospital, the researcher draws attention to that experience. The child becomes the focus of attention, the 'expert' to whom the researcher turns for information. "All of a sudden all eyes are on [the child] ...and these eyes rob [them] of ...[their]...taken-for-granted relation to [their]...voice and ...body. They force [them]...to be aware of [their]... experience while...experiencing it" (van Manen, 1990, p.35). The questions asked and the knowledge derived are guided, unconsciously or consciously, by both the researcher's and the participant's expectations of the context, and the impression each wishes to portray.

The researcher, in phenomenological research, makes explicit their prior experiences and associated assumptions toward the phenomenon under examination. This is done to address

> "the problem of phenomenological inquiry...that our "common sense" pre-understandings, our suppositions, assumptions, and the existing bodies of scientific knowledge, predispose us to interpret the nature of the phenomenon before we have even come to grips with the significance of the phenomenological question...We try to come to terms with our assumptions, not in order to forget them again, but rather

> to hold them deliberately at bay and even to turn this knowledge against itself...thereby exposing its shallow or concealing character" (van Manen, 1990, p.47).

This process was referred to by Husserl, as *bracketing*, and corresponds to the idea of removing the meaning mantle and immersing oneself in the world before returning to critically examine the mantle's structure and content. The degree of success one has with bracketing can affect both the data collection and analysis phases of the study, and involves a fine balance between the objectivity and subjectivity of the researcher. As van Manen (1990, p.27) states: "*a good phenomenological description is collected by lived experience and recollected lived experience - [and] is validated by lived experience and it validates lived experience*...sometimes termed the "validating circle of inquiry".

Phenomenology, as an approach to research, was chosen for its objective exploration of subjective lived experiences, and its willingness to put aside taken-for-granted understandings in order to see new possibilities, new meanings. This research study is : an inquiry, a critique and a validation of the experience of hospitalization for children with cancer - not just as seen by the participants, but also as perceived by the researcher. "Phenomenology is, on the one hand, description of the lived-through quality of lived experience, and on the other hand, description of meaning *of the expressions* of lived experience" (van Manen, 1990, p.25). Thus, it actively involves both researcher and researched in a joint effort - improved understanding is impossible without it.

Phenomenology and Validity

The aim of improving understanding brings us to the issue of validity. Quantitative research employs terms such as 'generalisable', and 'standardised', as measures of validity. These terms are not applicable to qualitative research. Firstly, qualitative research seeks to provide a full description of a phenomenon and generally employs small samples, that are non-random and non-representative, in order to gain greater depth and specificity of information. The applicability of results obtained is limited to the insights they provide for the particular context, subject group, and point in historical time being examined; that is, they have little generalizability.

Secondly, qualitative research is holistic, based on the premise that human action cannot be understood in isolation from its naturally occurring context (Packer, 1985). That is, its central belief is that the object of study (the child's experience), is firmly established in a social context (the hospital in particular, and associated contexts of family, school, neighbourhood and society as a whole). To understand an individual's experience an acknowledgment must be made that their construction occurred within a particular social context, and is necessarily influenced by that context.

The context of experience differs for each individual, and no attempt is made to control the research context. Standardisation of context is impossible in the real world, and would serve no purpose in the qualitative research study where the focus is on experiences of beings-in-the-world. This point is a reminder of the role of the *bricoleur*: to make a whole of what is available. The lack of standardisation highlights a further distinction between quantitative and qualitative research: quantitative seeks information in order to improve predictability and control, qualitative seeks information to improve understanding, and create more thoughtful "practical acting in concrete situations and relations" (van Manen, 1990, p.2).

This results in qualitative research not being conducted in an artificial, contrived setting, but in the natural setting where the object of study would usually be found. The hospital context provides the natural setting in which experiences occur, and is the logical place for interviews to be conducted, optimizing the immediacy of the experience for the child.

Although phenomenology, as a qualitative methodology, does not employ quantitative measures of validity, it is still required to meet certain evaluative criteria. Chamberlain et al. (1997, p.695) cite the development by Leninger (1994) of six evaluative criteria: "credibility, confirmability, meaning-in-context, recurrent patterning, saturation and transferability [and] other criteria by Stiles (1993) [of] coherence, testimonial and catalytic validity." These concepts are encompassed by van Manen's "validating circle of inquiry".

Put simply, it is acknowledged by qualitative researchers that due to the nature of knowledge as subjective, the results of any study are in themselves yet another subjective interpretation within a specific context. The ability of a study to promote understanding thus relies on the reader recognizing the 'truth' of an interpretation through its coherence with their own personal experience/ constructions, or being willing to place their own understandings in abeyance in order to view the phenomenon anew. Phenomenology has as its purpose the promotion of understanding and presents results in a form readily accessible to a wide audience, often providing direct quotes to highlight points. "A good phenomenological description is something that we can nod to, recognizing it as an experience that we had or could have had" (van Manen, 1990, p.27).

The current study has as its research question "What is it like to be a child with cancer in hospital?" The underlying assumptions which form a platform from which to explore this question, relate to ontology, epistemology, theoretical perspective and methodology, which correspond to realism, constructionism, interpretivism and phenomenology in the current study. These particular dimensions were chosen as appropriate to explore the research question, and place the researcher and participants side-by-side in a collaborative effort to improve understanding. This improved understanding can be achieved through the expression of experiences that the reader does not discount as outside the realm of possibility. The following chapter outlines the highest level of the scaffold - method.

CHAPTER FOUR

METHOD

This chapter is concerned with making explicit both the research process carried out, and the assumptions held by the researcher. The first section, therefore, deals with the recruitment of participants and the subsequent interviewing procedure. It also describes the stages of analysis undertaken. The second section contains the bracketed information deemed necessary in phenomenological research (as discussed in Chapter Three). A final section has been included in this chapter which addresses issues related to gaining ethical approval for this study.

NATURE OF THE SAMPLE

The participants were children with cancer who were diagnosed and/or treated at Wellington Hospital, whose coverage is from Wanganui across to Waiouru, to Wairoa, down to Wellington and Marlborough. There are three closely related reasons for the selected geographical area: physical accessibility, time and budget constraints. Physical accessibility refers to my being able to travel to the treatment centre for interviews with the children. The main treatment centres for children with cancer are Auckland, Wellington, Christchurch and Dunedin, and the children themselves live throughout Aotearoa. As I reside in Palmerston North the closest treatment centre is Wellington. This fact, combined with both budgetary and time constraints, made Wellington the most practical treatment centre to utilize.

The target group for the study were children aged between 5 and 15 years of age. Children younger than 5 years were not included due to the difficulty of gaining a detailed, descriptive account from individuals with immature verbal communication skills. The upper threshold was selected to restrict the range of developmental levels of the participants, as older children could be expected to raise additional issues which would necessitate a larger sample group to achieve saturation of information. Furthermore, the physical environment of children aged 15 years and over is different as they are treated on the adult oncology wards. This raises a whole set of further issues, and requires investigation on its own merits.

Consistent with the phenomenological approach, personal accounts were the focus of the study, specifically those of the hospitalization experience. The accounts were elicited from children diagnosed with cancer who had been in treatment within the last two years. The initial plan for the research was to interview currently hospitalized children in order to tap into the immediacy of the experience within the hospital environment, thereby receiving an account unmediated by processing and distance from the situation.

There are several reasons why the inclusion criteria were expanded to include children who had had treatment within the last two years. Firstly, the drawn out process of ethical approval resulted in my missing an earlier deadline for the Child Cancer Foundation newsletter, effectively diminishing my data collection by a month. Secondly, the restriction on directly approaching parents left the burden of responding on parents who were stressed and pre-occupied; (both of these points will be discussed later in this chapter). Thirdly, during the time available for interviewing, many of the children being treated at Wellington Hospital were below the inclusion age of 5 years. Finally, due to a zero response rate for currently hospitalized children, it was necessary to broaden the inclusion criteria as the overall aim of the study - to hear from children about their perceptions of being in hospital - was still seen to be worth investigating.

The intended initial sample size was five participants due to practical considerations, as I had hoped to conduct all the interviews over a two month period, during which time the number of children on the ward who fit the inclusive criteria may have been limited. Although qualitative strategies typically continue adding participants until no new information is found, that is saturation is achieved, a maximum of 10 was set in the current study. However, the non-response rate over a five month advertising period resulted in a broadening of the inclusion criteria, and a minimum of three participants being set, with five being desirable.

The addition of participants which, in phenomenological studies, is done to increase the depth and range of coverage of a phenomenon by searching out accounts not consistent, or possessing a hitherto unknown behaviour or concept, was difficult to incorporate in the current study. Due to recruitment difficulties, there was a low number of available participants. However, during the analysis stage, it became clear that saturation had been achieved.

Seven children, five male, two female, were interviewed, ranging in age from 6 years 8 months to 11 years 2 months. Four of the children were diagnosed were ALL, one with a Wilm's Tumour, one with Medullablastoma, and one with Non-Hodgkins Lymphoma. The time elapsed since last treatment varied from 7 months to 17 months. The time spent in hospital as an inpatient varied from 12 days to 6 months. (Full details are provided in Table 1 below). All interviews were conducted in the child's own home.

Table 1

Participants' Diagnosis and Treatment Information

Participant	**Diagnosis**	**Age at Diagnosis**	**Length of Protocol**	**Time in Hospital**	**Last Treatment**
Chipmunk	ALL	4 yrs 6 mths	2 yrs	4 weeks (est)	Jun '99
Freeze	ALL	5 yrs 6 mths	2 yrs	30 days	Sep '99
Blah Blah	ALL	5 yrs 4 mths	2 yrs	12 days	Sep '99
Fairy	ALL	3 yrs 2 mths	2 yrs	4 weeks	Nov '98
Wavy Gravy	Wilm's Tumour	5 yrs 4 mths	1 yr	6 months	Dec '98
George	Medullablastoma	5 yrs 11 mths	1½ yrs	5 months	Dec '98
Bill	Non Hodgkin's Lymphoma	8 yrs 9 mths	1 yr	4 months	Oct '98

There are several ways in which age seemed to be linked to patterns within the accounts, the most notable of which is *time since end of treatment*. This is not the equivalent of time since diagnosis, as all the children were very close in time since diagnosis, but three of the seven children had shorter treatment protocols. Time since diagnosis did not appear to influence the accounts given.

Four of the participants were nearing 18 months since their last treatment; three of these children had tumours, and although their overall protocols were shorter, they spent more time in hospital during treatment. The remaining participant had ALL (Acute Lymphoblastic Leukemia). This participant was the youngest at diagnosis (3 years, 2 months), and had completed treatment at the age that the remainder of participants were diagnosed (5 years 4 months). Children who were nearly 18 months from last treatment exhibited a greater willingness to discuss their hospital experiences, reported more interactions with people other than family, and were able to report more positive events while in hospital.

Two of the remaining three participants, had completed treatment within the 6 months prior to the interview, and the final participant completed treatment in the preceding 12 months. All of these children had ALL, and their treatment protocols were of two years duration. This group of children were less willing to discuss their experiences, and less articulate about their perception of hospitalisation.

RECRUITMENT

Ethical approval gained from both the Wellington Ethics Committee (responsible for research undertaken within institutions governed by Central Health), and the Massey University Human Ethics Committtee, placed restrictions on my directly approaching potential participants and their facilities. Therefore advertisements were created.

A3 size posters were placed on Ward 18 and the Parents Room attached to the Paediatric Outpatients Clinic at Wellington Hospital; in the Ronald McDonald Family Room, Wellington Hospital, and in the Paediatric Clinic, Palmerston North. Leaflets were also left at Ronald McDonald House, Wellington. An invitation was placed: in the Child Cancer Foundation's (CCF) October newsletter; in the Manawatu branch newsletter of the CCF in both December 1999, and March 2000; and in the Camp Quality Companion Network Newsletter, March 2000. In the event only one participant resulted from this recruitment process (Appendix B). The remaining participants resulted from conversations between a parent of the Manawatu branch of CCF and another parent, whose child was in remission. This child became the second participant and the mother independently initiated contact with other parents, requesting participation of their children in the study.

Response Process

When a parent made contact an information form (Appendix C), was sent. A follow-up phone-call was then made to answer any questions and ask if they would like to participate. If the response was 'No', no further contact was made. No parents who received information declined to have their child participate. On gaining verbal consent, arrangements were made for the interview. On arrival at the child's home a written consent form was given to the parents (Appendix D), and an assent form was given to the child (Appendix E). In the ethical application for my study I had stated from the outset that in order for a child to participate **BOTH** parents and the child had to agree to participation. Once both parents and child had signed their forms, and any questions were answered, the interview took place.

DATA COLLECTION

Setting

The setting is an important factor for interviews. The interviews were to be conducted in the hospital setting - that is, Ward 18 - to try to fully capture the immediate, and current, experience of the child. The immediacy of the hospital experience was seen as having its own set of problems. For example, the state of health of the child - mental, emotional, physical and social - might not always have been adequate to participate fully in the interview. Flexibility in the interview schedule had been allowed for a 'down' day, and also for the possibility of needing to carry out the interview in two or three shorter sessions.

After the inclusion criteria were altered, children were interviewed in their own homes. This brought with it a changed set of advantages and disadvantages. The advantages included the child being in a familiar setting which made gaining rapport significantly easier; the setting being more comfortable and relaxing; and the child's health being of less concern. The disadvantages included the presence of siblings and parents in the vicinity possibly influencing the responses from the participant; and the presence of distractions, such as television and toys.

Procedure

Firstly, having gained informed consent from the parents, and assent from the child, an initial interview was held with the parents and child. This interview served the dual purpose of further gaining the trust of the parents, and allowing the child to become more familiar with me. During this interview a series of demographic questions were asked (Appendix F). This interview was not recorded.

The interview with the child then took place. The interview took place between the child and myself. In two cases a parent/s were present in an adjoining room and were able to hear what was being said. In another case, the mother was present and contributed to the interview. Her comments were not included in either the transcript, or the analysis of the interview. It was seen as important to interview the child on their own in order to foster an atmosphere of true expression, and obtain the most candid information regarding the participant's hospital experience. The presence of parents was seen as a possible influence on children's responding and may have resulted in a lack of free expression and the selectively monitoring of their account. The interviews were audio-taped, then transcribed by myself.

One week after the interview with the child a follow-up phone call was made to the participant and their parents. At that time I asked if they had any questions about the interview, or study. Finally, after six months a copy of the tape was sent to the child and another phone call made to answer any questions, or receive any comments regarding the interview process, and its effects on the child.

The Interview

The collection of data occurred via interview, which provided the most effective means of obtaining the stories of paediatric oncology patients. The specific interview technique employed was that of an in-depth, semi-structured, semi-standardized interview. This method allowed the participant optimal opportunity for self-expression without the imposition of a formal structure, or set guidelines, by the researcher.

The child was encouraged to talk about their hospitalization experience, but the specific topics within this area that were communicated to the interviewer were self-selected. The interviewer took her cue from the respondents and "..while it tends to be conversational in style researchers might ask provocative questions or ask respondents to explain their statements, behaviour, or attitudes" (Bauman and Greenberg Adair, 1992, p.10).

In addition to allowing optimal self-expression, this interview technique was chosen for several other reasons. Firstly, because the direction of the interview was guided by the participant and questions related directly to what was said, it becomes more likely that the accounts received would accurately reflect the participant's perspective rather than the assumptions/interests of the researcher. Secondly, the conversational style placed less pressure on both the respondent and the researcher, and more closely resembled natural interaction, placing both parties on an equal footing. This is vital as qualitative interviewing techniques require at least a moderate level of rapport in order to encourage self-disclosure by the participant (Eiser and Twamley, 1999).

Thirdly, without a set schedule of questions to adhere to the researcher was more free to attend to the account and take note of behavioural factors such as posture. Fourthly, this method firmly established the child as the possessor of knowledge and the researcher as willing to be informed. This served the dual purpose of eliminating the common power imbalance between child and adult, and assisting in the building of rapport. Fifthly, the interactive nature of the interview provided the child with evidence of having been listened to, heard and understood. Finally, through the articulation of their experience, the participants may also have gained some understanding of their world, and their self-in-relation (Ivey, Ivey and Simek-Morgan, 1997).

Bearing the above points in mind the interview commenced with the general question: "What is it like to be in hospital?" Prompting questions were used, such as: "What is it like to talk to the doctor?" "What is it like when you are having (..that..) treatment?" "What happens when you can't sleep like that?" (Appendix G).

DATA ANALYSIS

In all, seven interviews were conducted, varying in length from 20 - 45 minutes. One child was brief in answering questions, but very expressive in body language; the information from both the verbal account and field notes taken from the interview are included. Another child felt disinclined to discuss their hospital experience; the transcript of that interview was still included in the analysis as the two responses given to interview questions were seen to be valuable.

In Chapter Three, I discussed the role of van Manen's (1990) first two research activities, namely turning to a phenomenon which interests us, and investigating the experience as we live it. The remaining four research activities- Reflecting on the essential themes which characterize the phenomenon, Describing the phenomenon through the art of writing and rewriting, Maintaining a strong and oriented relation to the phenomenon, and Balancing the research context by considering parts and whole - were involved throughout the analysis of the transcripts. In addition, Interpretive Phenomenological Analysis (IPA) was utilised (Smith, Jarman and Osborn, 1999).

IPA is a form of analysis which recognises the importance of both situation and language. In the current study, attention to the language and situation of the hospital highlights their role in the determination of individual coping responses. IPA attempts to understand from the transcripts what the participants think or believe about their experience in order to say something meaningful about the perceptions those thoughts and beliefs reflect. This relates to IPA's "belief in and concern with, the chain of connection between account, cognition and physical state" (Smith, 1996, p. 265). The aim of IPA is the exploration of the individual's perception of their world in an attempt to gain, as much as possible, an insider's view of that world. Gaining an insider's view may be assisted by the delineation and interpretation of commonalities and differences that may exist between participants accounts; this process may provide information on the gap between shared perceptions of an experience, and those that are unique to the individual.

The analysis of the children's accounts contained six major steps: transcription of interviews, looking for themes, coding of theme categories, recording marked excerpts separately with the relevant theme category, intuiting overarching processes, writing the analysis. The first step was the transcription of the interviews which I carried out myself. I include this as a stage of analysis because it involved a process of careful attention to content, but also brought a greater familiarity with the overall tone of the interview. In many ways, I was able to experience the interview again without needing to be concerned with conducting the interview process. During transcription I considered those areas where I had not clarified information, and topics which might have benefited from extension. It was both a valuable exercise for the development of my interviewing skills, and an opportunity to hear information and cues that I had missed during the interview.

This first step in the analysis process reflects van Manen's research activity named: Maintaining a strong and oriented relation to the phenomenon. Through interaction with the recorded accounts and the transcription of these accounts, I was constantly reminded of my responsibility to keep participants as the central focus of the research. Questioning of my interviewing skills also engaged me in the process of considering better ways in which to talk and act with children with cancer.

The second and third phases involved the use of IPA. In the first instance I chose one of the transcripts and read it several times, looking for themes, and coding line by line in the left hand margin of the transcript. The themes which emerged were intuited from the transcript. Sometimes the themes were phrases summarising a central idea, (e.g. 'no interaction with others'), in other cases they were descriptive, (e.g., physical environment). The aim of these themes was to describe the myriad concepts that are often conveyed by one word or phrase.

The following stage required creation of theme titles for the notes made in the left-hand margin. These titles were considered to capture succinctly the essence of the themes (Smith et al., 1999), and were recorded in the right-hand margin. For example, the themes physical environment, 'cool' vs 'normal', bathroom and toilet, and grading of room were grouped under the theme title: 'status'. These two stages involving the creation of themes and theme titles, mirror van Manen's (1990) stage of reflecting on the essential themes that characterise a phenomenon. These themes and their titles operate to organise our interpretation and answer the question "What is this an example of?".

As themes recurred during analysis they either floated or acted as magnets for other themes. In this way, during the process of coding theme titles for the first transcript, it was possible to see patterns emerging, and ways in which some themes fitted neatly under one title, while others seemed relevant to several. This is an important point as van Manen cautions us to recognise that themes will never totally explain that which they name, they are merely an attempt at uncovering yet another facet of a mystery. At the end of this stage I possessed nine theme titles - knowledge, relationships, feelings, schoolroom, treatment, food, language, status, and activity - and 168 themes. Having completed the coding of one complete transcript, I proceeded to repeat the above process for the remainder of the interviews. Some transcripts yielded new themes, which I then searched for in the earlier transcripts; no new theme titles were created.

The fourth step entailed condensing all the transcripts. The condensed transcripts omitted many interviewer comments which were unnecessary for maintaining comprehension as they merely reflected back to participants their own responses. On average the transcripts were reduced by a third. The condensing of transcripts required that I again interact intimately with the accounts of the children and recognise the contribution each made to the understanding the hospitalisation experience of children with cancer. Page references for instances from the text which characterise the meaning of a theme, were then entered alongside the relevant theme. Van Manen's reflecting on essential themes plays a part in this stage. It was necessary at this point to resist the temptation of favouring some children's accounts because of the rich data they provided and because they coincided with my own perceptions. Reminding myself of the fabric of my meaning mantle allowed me to place it back on the shelf and instead, ask of each part of the condensed transcripts: how does this extract contribute to our understanding, and which theme does it relate to most?

During the fifth stage hours were spent arranging and rearranging the theme titles, searching for a meaningful way of naming and describing the patterns that I had observed through my interaction with the transcripts. However, it was only during the final stage of writing up the analysis that the overarching patterns really took shape. This final stage was done in the first instance direct from the condensed transcripts, and various theme titles were split and shifted from place to place as I reassessed their relationship to the children's accounts. During the writing process I found it necessary to go back to the original transcripts and summarise my understanding and interpretation of each individual account. Throughout the analysis I was attempting to balance the individual accounts with the contribution they made for overall understanding of the hospital experiences of children with cancer.

This process of interpreting the data and writing was far from simple; nor did it ever feel complete. Even now there are interpretations which are not expressed within this thesis. Although this can impart a sense of incompletion to the researcher, for van Manen (1990), it is an accepted characteristic of maintaining a strong and oriented relation to the exploration of a phenomenon. In fact, it can provide a measure of the depth of that exploration. According to van Manen, depth "gives the phenomenon… [both] its meaning and its resistance to our fuller understanding" (1990, p.152), and, can be shown almost as much in what is left unsaid, as what is said. Admitting to the incompleteness of the interpretation involves a recognition that we are reaching beyond the readily observable facade of a phenomenon - the hospital experiences of children with cancer - to that which lies beyond, which has become forgotten or hidden, and attempting to return it to the foreground of our view, in order to act more consciously. At the core of this process is also the recognition that there is still more meaning which lies behind the small part we have been able to uncover.

> "To the question, "Have I done anything heroic?" I'd say learning to live in a state of not knowing and not just grabbing at an easy solution or a quick-fix philosophy to carry me through, to make me feel secure and in control. Waiting, being patient in the chaos, is my achievement. It takes courage to knowingly live with some degree of incomprehension, to not be frightened by the black holes of life. The people who can eventually achieve some measure of calm and not turn their back on the not knowing but hold the questions, hold them open and live, that seems to me to be heroic" (Leunig, 1998, p.6)

BRACKETED INFORMATION

My mantle of meaning represents my values and perceptions gained throughout my life journey. While this section is not intended as an autobiography, it is nonetheless necessary for you to know some of the fundamental experiences which have brought me to this time and place. I remove that mantle in order to describe its history, how it came into existence, for both myself and the reader. This is done for several reasons. Firstly, it is part of the phenomenological process of making explicit my prior knowledge and beliefs. Secondly, it provides the reader with a gauge for determining the degree of success I have achieved in holding myself apart and letting the children's voices be heard. Finally, at the end of this study, this bracketed information will be a means to evaluate the 'fit' of my mantle with the experiences reported by the children, and will ultimately measure my own personal learning and growth.

At the beginning of my life a mantle was given to me from immigrant parents, a gift of strong religious values and high standards for behaviour and achievement. This mantle grew and changed, as did I, throughout my childhood and adolescence. In later years I added colour and texture through my training and work as a pre-school teacher, social worker and youth worker. In particular, my education has given me a belief in the power of the individual mind to influence the world, and also the role the environment plays in the individual's formation of perceptions of that world. This thesis completes a new portion of my mantle by adding the study of psychology to that of education and sociology. The lining of my mantle, that which gives it shape and support, is made up of my spiritual beliefs. I believe that each person has chosen their life path for a reason, that each of us has both a lesson to learn, and a lesson to impart.

The information which follows forms the fabric of my meaning mantle specifically related to children with cancer in hospital. It is difficult to determine how much detail is needed, and as this portion of my mantle has been 14 years in the making, I have had to make decisions as to what to include, and what to omit. There may be aspects of my account which I will later wish I had omitted, and others which I will wish I had included. Such is the ongoing nature of writing, but for today I have done my best.

In 1986 my life changed, though it was many years later that I realised the extent of that change. On December 27th I was on a bus waiting for a child – my camper – to arrive at a rendezvous point. The name of the camp was Camp Quality, and the children it catered for were all children with cancer. On the ride from the camp site to the rendezvous I had been chatting to the camp director, asking him about the numbers of children coming. I got a shock when he informed me that there had been 32 children due to come, but that two children had died, and two had been hospitalised. We had had an orientation previously, and medical facts and figures had been given to us, but this really brought home to me the precariousness of these children's existence. That was when I first realised that I didn't know much about what it was like to be a child with cancer.

I have now attended ten camps, soon to be eleven, and each year I learn a little bit more about the experiences these children have had in their lives. My exposure to the issues in paediatric oncology increased when I became a volunteer at the Ronald McDonald Family Room, and volunteer relief weekend manager of Ronald McDonald House in 1996, and later, after my move to Palmerston North, I joined the Manawatu branch of the Child Cancer Foundation. In March 2000 I accepted the position of CanTeen coordinator for the Manawatu/Wanganui branch, extending my area of involvement to include young people. CanTeen is a peer support group for young people aged 13 - 24 years, affected by cancer, either themselves or their sibling.

The information I have gained about children's experiences of hospitalisation has come from a number of sources - parents, siblings, grandparents, nursing staff, support staff, and written material. It will be difficult to hold these ideas at bay, and not allow them to colour my interpretation of the children's accounts. By continually going back to the transcripts and checking my interpretations, I hope to avoid contamination by the meanings of others.

Although the information gained from the above sources has been valuable and enlightening, my main source of information has been the children themselves through their directs comments to me, and from my observations and interactions with them in their home settings, the hospital, and at Camp Quality.

What is it that forms the colours, texture and form of my meaning mantle of the experience of being a child with cancer in the hospital?

- Children's physical condition affects their psycho-social adjustment.
- Boredom is a constant source of frustration, anger, sadness and disappointment, all of which are capable of influencing their physical condition.
- A parent's presence is important for their sense of security, and children trust their parents to make decisions in their best interests.
- Interactions with medical professionals can influence both the physical and emotional reactions of the child.
- Social and psychological support is often inadequate.
- Hospitalisation often robs children of a sense of control.
- Children don't physically react in the same way to treatments, or being hospitalised.
- Children cope differently to having cancer and being hospitalised, and the way in which they cope affects their adjustment.
- Children protect their parents.
- The child's voice is often not heard, and their behaviour often misunderstood.

Over the last 14 years I have had times of feeling helpless when faced with a child's pain and suffering. I didn't like it, so I began to search for ways to be with the child during those times; I read books, went to public lectures, meditated and prayed. The lessons I have learnt from these children are to be as authentic in living as possible, to live without regret, and always to remember that we are all connected.

> "I've observed that many people who are struggling with ...some crisis...come down to some basic undeniable truth, they become almost their spontaneous selves, and with this honesty they have a kind of dignity. If we're suddenly confronted with real human suffering our compassion is awakened and there's a sense of something beautiful present..." (Leunig, 1998, p.12).

My answer then, to that feeling of helplessness, is to be totally present, to be a listener, to be comfortable with silence, to accept the gamut of emotional expressions, to accept the intuitions that I receive, and thus to ***see*** the beauty present in the child. It has taken me half a lifetime to realise that that is enough.

My meaning mantle is coloured with threads of physical information, my training in education, sociology and psychology, and those of spiritual values. It is sewn together with what the children have taught me about the human condition: the strength, the courage, the humour, the compassion, the selflessness, the love, and the ability we have to survive in the face of great suffering. All this I have attempted to put aside in order to represent the children's accounts to you, and to form a picture of the essence of that experience.

ETHICAL APPROVAL

The thesis, with its focus on method and results, can often gloss over some of the very real and time consuming components of the process of getting a study approved. The process of gaining approval for the current study from health professionals in the area, and ethical approval from two committees, was taxing both personally, and in terms of time.

Active support, rather than mere compliance, from ward staff and the paediatric oncology team was seen as essential for the recruitment process, and for providing an interested reception for the research findings. As these are some of the groups I wished to inform by providing greater understanding, with a view to influencing practice, their support was to be encouraged. Support was gained from the Director of paediatric services, and the paediatric oncologist. However, I found it disappointing that the Child Cancer Foundation were unwilling firstly, for me to approach families directly regarding participation, and secondly, for their family support person to make initial contact with families on the ward. I feel this greatly affected the response rate.

This response reflects a perceived reluctance to support psycho-social research, and is in marked contrast to the Foundation's financial support of medical research, in which families are encouraged to participate. Also of concern was the active resistance from psycho-social health professionals to the proposed method of the research. Whilst some of their concerns were valid, their reluctance to accept that these had been considered and were catered for within the study design, was a source of great disappointment.

This study was approved by two ethical committees: the Wellington Ethics Committee (responsible for research undertaken within institutions governed by Central Health), and the Massey University Human Ethics Committtee. Application was made to the Wellington committee in March, and approved in May; an application was made to the Massey committee in May, and approved in September.

It became apparent during this lengthy process, that I had chosen to study an area which combined four elements that people were 'touchy' about - namely children, cancer, interviews alone with the child, and hospitals. The depth of reaction was somewhat of a surprise. Suspicion of the study can, I feel, be traced to several common misconceptions about children: that they are fragile, lack understanding, are not able to voice an opinion, may not be able to communicate their experiences, and that talking with children with cancer about their hospital experiences is necessarily traumatizing. While these issues certainly need to be considered, the proposed research had addressed them; furthermore the Wellington committee had already approved the study.

It would appear that there is a need to have national guidelines so that approval by one ethics committee should be sufficient to meet the requirements of others. This process also raised the question for me of: What is the role of the ethics committee? It appeared that some members on the Massey committee saw it as obtaining a guarantee that no harm would come to the participants, rather than ensuring that every possible effort has been made to protect the rights of the participants, and provide back-up in the unlikely case of something untoward occurring.

Unnecessary delays of this type, which create additional difficulties to the already taxing research process, can be responsible for research with children often getting placed in the 'too hard' basket. It is questionable as to whether a qualified child psychologist would have received the same difficulties gaining approval, but it shows a lack of trust when someone who has worked in this area for 14 years is not looked on as competent enough to carry out interviews without causing psychological distress to the child! There were several tempting moments when this study almost got placed in that 'too hard' basket.

CHAPTER FIVE

RETAINING A SENSE OF SELF-AS-NORMAL

Analyses of the interviews found two main themes underlying the children's accounts. The themes are 'Retaining a sense of self-as-normal', covered in the current chapter, and 'Incorporating multiple selves', described in Chapter Six. In every person's story there are aspects which are unique to their experience, and those shared by others. The shared aspects exist by virtue of being human, and due to interaction with similar environments, during a similar period of time. These analyses attempt to portray both that which is unique, and that which is shared, in the hospital experiences of children with cancer. In the previous chapters, a great deal has been said about coping, control, support and meaning. While this chapter and the one to follow will make implicit reference to coping, it will not be discussed in any great detail. The implications of the analyses for coping, will be discussed in Chapter Seven.

Cancer diagnosis and treatment, as outlined in Chapter One, brings about major changes in a child's life. Hospitalization, as a foreign environment, can be intimidating to a child, especially with the associated treatments which occur there. The children's accounts show that during this time maintaining some sense of normalcy is fundamental to coping with the stressors involved in cancer and its treatments. What came through clearly in the children's accounts was their own unique character, but there were also aspects commonly found in children, such as the desire to play. There was evidence of efforts to maintain both their individual and shared characteristics, even while in a different environment.

The theme 'Retaining a sense of self-as-normal' revolved around the children's efforts to retain some sense of stability in their daily lives, both in their interactions with people and their activities. These efforts were aimed at holding on to a sense of self-as-normal, a child who is essentially the same, even though they have cancer. The retaining of self-as-normal contains two sub-themes: 'Maintaining links with familiar people', and 'Becoming 'at home' in the hospital'. Maintaining links with familiar people involves keeping contact with those people who formed part of the child's life pre-diagnosis - family, friends, classmates and school personnel. Becoming at home in the hospital relates to evidence in the children's accounts of making themselves familiar with both the physical environment, but also with the rules and routines of the hospital.

MAINTAINING LINKS WITH FAMILIAR PEOPLE

The familiar people mentioned, to varying degrees, in the children's accounts were: family (both nuclear, and extended), friends, classmates, and teachers. References to family in the accounts was divided between Mum, Dad, siblings, and extended family. All participants saw the presence of a parent as important, while visits from siblings were seen more as a distraction. Interactions with friends, classmates and teachers varied in frequency and quality and individual children placed different emphasis on the importance of these people.

Parents

One parent was present, and stayed on the ward for the hospital stays of all the children. Even though the importance of a parent being present was acknowledged, very few references were made to activities or interactions with the parents. While their presence was largely taken-for-granted, younger children explained any periods of parental absence. Chipmunk mentions his mum when describing an occasion of being on his own. He explains her absence, while also providing an idea of the short time frame involved.

> ***"Did you ever stay in the hospital on your own, without Mum there?***
>
> *Hmmm, when my, when my mum went to the school room to get toys."*
> *(Chipmunk - 7 yrs, 4 mths)*[1]

---

[1] Extracts from the transcripts sometimes include the researcher's questions where these are needed or helpful for the reader to understand the sense of the excerpt. The researcher's questions are printed in bold type.

A longer absence is described by Fairy in her discussion of surgery. Surgery rated as the worst treatment for Fairy because her mother wasn't there with her throughout the procedure. Although her mother was with her up until the time she fell asleep, Fairy's knowledge of her subsequent absence, created a dislike of the procedure.

> *"**Can you tell me why** [you don't like surgery]**?***
>
> *It was, when, when I, when they took me asleep, mum goes.*
>
> ***Oh, right, you don't like it when mum goes, when they put you to sleep?***
>
> *(head shake)" (Fairy - 6 yrs, 8 mths)*[2]

The dislike of surgery was compounded by her mother also not being there when she woke up, and having an unfamiliar nurse there instead. The unfamiliar room and personnel made Fairy feel 'sad', which she felt would be helped by the presence of her mother when she woke up. Parents as a reassuring presence was also key to another participant's reference to his parents' presence during a computed tomography (CT), scan.

> ***"Does it make you nervous sometimes?** [CT scan]*
>
> *Yip, sometimes. But mum and dad are allowed in...I've gotta wear a big vest, it's heavy." (Bill - 11 yrs, 2 mths)*

While Bill sees himself as fairly used to the hospital procedures, he still acknowledges his parents as helpful in alleviating feelings of nervousness. Parents, in addition to being reassuring, also performed the role of information filter. They are the channel of communication between medical staff and children, and children trust them to have the necessary information about what is going on, and the ability to answer any questions they might have. This is particularly the case for information about procedures.

> ***"What about while you were still in hospital? Did you know what was happening then?***

---

[2] Square brackets [ ] are used to indicate either a reference to a previous part of the transcript, or to supply a generic term to protect the confidentiality of participants. Dots ... are used to indicate pauses in the children's speech, the joining of participants' responses from separate parts of the interview, or the omission of interviewer questions where these were not needed to assist comprehension.

> *Yeah.*
>
> ***Who told you what was happening then?***
>
> *My Mum.*
>
> ***So if you had any questions, is that who you would ask?***
>
> *Hmm, yeah" (Chipmunk - 7 yrs, 4 mths)*

Parents' roles are mostly unspoken, and seem to be as taken-for-granted as their presence. In the following extract, Bill is quick to wake his father up for failing to meet expectations of his role.

> *"...squirt dad, when he wouldn't wake up for the night, and I had to get a new bag of saline or something...and he wouldn't wake up, so I squeezed it, squeezed it on him (laugh)" (Bill - 11 yrs, 2 mths)*

From the above accounts we can see there is an expectation, on the part of children, that parents will ensure their children's needs are met, and that they will be present during times of distress. These reflect common expectations of parents, held by normal children, and society as a whole. These expectations presume a sense of trust is present between parents and their child.

Trust between parent and child is a taken-for-granted aspect of their relationship. This trust can be seriously tested in the paediatric oncology experience as parents are not always able to meet their child's needs, nor be present at times of distress, for example, post-surgery. Also, children from a young age learn to defer to the instructions of parents as to what is in their best interests, even though they may not like it. In the paediatric oncology experience this means undergoing painful procedures and treatments, which challenge the strength of the bond between parent and child, and the role of the parent as protector of the child.

The expectations of parental presence during times of stress is an example of a coping response - seek social support. This was found in the majority of the children's accounts, and relates to the role of parents as decisions makers in the child's life. It could therefore be posited that through seeking the support of parents the child is in fact gaining a sense of control through knowing that the people who they trust to act on their behalf, are present. This was reflected through the accounts by a sense that if a parent was there, the experience was better than if they were absent.

Siblings

Visits from siblings varied in frequency and the degree of emphasis placed on them by participants.

> *"...And mum, and my mum and dad, and my brothers came and saw me, see me in hospital.*
>
> ***And what did you do with them when they came to visit?***
>
> *Uh, lie on my bed and laugh, and talk...(comment from mother)...and throw pillows." (Bill - 11 yrs, 2 mths)*

Bill enjoyed having his siblings come in to visit him and his interaction with them took the form one would expect to observe in the home - watching t.v., talking, playing and fooling around. Fairy also enjoyed having her siblings come to visit as they would give her 'big hugs'. These visits were so important that Fairy uses them to explain why she prefers being in a room on her own.

> ***"And which do you like best, being in a room on your own, or with other people?***
>
> *Um, being on my own, 'cause, 'cause it, 'cause it the mummy and daddy don't come in if um, daddy, [siblings] don't come in if, if there's people around... so it's , it's just best if I be on my own...With mummy." (Fairy - 6 yrs, 8 mths)*

Siblings are a part of daily 'normal' life, and their visits are seen as important in retaining a sense of normalcy. The ability to carry out normal activities with their siblings was common to the children's descriptions of visits.

Peers

Both neighbourhood friends and classmates featured in participants' talk about contact with people who formed part of their world pre-diagnosis. When discussing radiotherapy, Bill describes how seeking social support from his classmates helped him cope with his sadness.

> ***How did that make you feel?***
>
> *Um, sad sometimes, but I sent faxes to my class a lot...Sent a real as long one.*
>
> ***And did they send things back to you as well?***
>
> *Yip. They sent stuff.*
>
> ***And did any of them come in to visit you?***
>
> *Um, my friend...did...Yeah, he came in visit me, and bought me a parcel of goodies...[friend], yeah my friend ...*
>
> ***that make things a bit better having visitors?***
>
> *Yip." (Bill - 11 yrs, 2 mths)*

Visits from peers were welcome but not always possible due to the child's physical health. However, letters and gifts received were highly valued, some children reporting that they had kept the letters.

> *"**What's it like being away from your friends while you're in the hospital?***
>
> *It's alright.*
>
> ***Do your friends sometimes come and visit?***
>
> *Yeah...But they make me stuff...Christmas things, ...tapes...I don't know." (George - 8 yrs, 3 mths)*

> *"**Did you play with any of the other things down in the school room?***
>
> *Most of the time they, they had to bring it to me...And my, my class were, in room 8, and they kept sending me big letters so I had to send one back...And I've got a book about it.*

> ***You've kept all their letters and things that they sent you?***
>
> *(nod)*
>
> ***And what did you do with those while you were in hospital?***
>
> *Um, um I just gave them to mummy and then um, when I got back to school, when it was my first day back , I got back to school and they, 'cause I just finished one of the operations and I come back to school, mummy took me in with [sibling] and I didn't know what was happening, and it was a surprise party with my sister and my class and my aunty and cousin...were there. And they had lollipops and stuff in there." (Wavy Gravy - 7 yrs, 6 mths)*

In the latter extract Wavy Gravy spontaneously brings up her classmates, and the contact they had maintained with her. Throughout her account Wavy Gravy made reference to school friends and her boyfriend, whom she missed, and whose absence made her feel 'sad'.

Teachers

In some cases teachers came into the hospital to visit.

> ***"And did any of them [teachers] come in to visit you?***
>
> *... [school principal], and ..., my teacher, and ...that's about all." (Bill - 11 yrs, 2 mths)*

> ***"So apart from your boyfriend did any of your friends come into school to visit you? Into the hospital to visit you?***
>
> *Uh, no but my, one of my, uh, [teacher] the one that used to teach the younger kids came in, 'cause that's when I got sick...when I was in her class...and she, she, she came in and gave me a present and she came in with a present from the principal and it's that, it's a teddy and I've still got it. And he kept, and I kept going to school and he kept asking me:*

> *How's that teddy of yours? And I go: He's fine. I hope you're looking after it. (laugh)" (Wavy Gravy - 7 yrs, 6 mths)*

Contact with teachers aided in a sense of normalcy, allowing the children to focus on both their life pre-hospitalisation, but also on their return to school.

The importance of siblings, peers and teachers in retaining a sense of normalcy lies in the link they provide for the child between the past, present and future. A major benefit of this link for siblings, peers and teachers is an awareness of some of what the participants are going through during hospitalisation. The benefit for the child is the knowledge of others' awareness, and a reduction in feeling 'different'. This can result in an easier re-entry to both family and school life post-hospitalisation. In addition, the contact can assist the child in developing a sense of self-worth - my class wrote to me, therefore they must miss me, and I must be important to them.

A marked difference was found in the references to school, between those children who had started school pre-diagnosis, and those who started school while undergoing treatment. Children who had already started school had formed friendships with peers and teachers, which were seen as important to maintain. Their accounts generally made greater reference to seeking social support from these groups, while the younger children relied on their families for social support.

This section clearly shows the importance of familiar people in retaining a sense of normalcy. Their presence is seen as both a support during the difficulties faced in hospital, and a link between their past, present and future. These people also play a role in the development of a sense of self which will be discussed in Chapter Six.

BECOMING AT HOME IN THE HOSPITAL

This activity was central to some accounts while others engaged in little effort to settle in. 'Becoming at home' involved engaging in child-like activities, becoming familiar with the physical environment, and gaining knowledge of the rules and routines of the hospital. The knowledge gained was equivalent to that of the home environment - the places to play, where the best toys are located, who will enforce the rules, who will bend them, what is available, acceptable, and what will get you into trouble.

Engaging in Child-Like Activities

The type of play engaged in varied between children but was inevitably labeled as fun, as opposed to boring. The fun entailed laughter, mischief, and creative expression to varying degrees for each of the participants. The fun activities which involved other children from the ward often contained a competitive element.

Childhood is a time of life where jokes and laughter are frequent, and seen to represent happiness and adjustment in the child. Some participants managed to engage in mischief within the confines of the ward environment.

> *"Yip, like sometimes when the nurses come in [preferred nurse] would give me a 60, or 30, or 20ml syringe and he goes squirt them when they come in, and we'd fill it up with water and 'phlut'...(miming squirting)(laugh)... and they always get saturated. We had a water fight one time." (Bill - 11 yrs, 2 mths)*

Here the use of medical equipment is re-invented to accommodate a desire for fun. The use of resources found at hand on the ward, and their transformation into play objects can also be seen in this description of a fun time:

> *"And sometimes my big sister we had, I had a wheelchair and the nurses said oh, go on, 'cause my um friend ... she um, she had another wheelchair so me races were having wheelchair races..." (Wavy Gravy - 7 yrs, 6 mths)*

Interaction with others on the wake is evident, along with the use of wheel chairs for an activity other than its original purpose. Other mischief occurred when Freeze received a gift:

> *"he bought me a big (mumble)...A big remote control car.*

> ***Who did you run over with that?***
>
> *(smirk) Nobody.*
>
> ***Chase anyone down the halls with it?***
>
> *(head shake)...Oh, yep...this boy ...across from me." (Freeze - 8 yrs)*

This discussion brought animation to his voice and energy and alertness to his body posture, indicating the physical responses which result from the use of mischief/humour. Although this change in physical demeanor was most evident for Freeze, there was a similar pattern for other participants while describing fun activities. When discussing boring occasions the tone of voice would drop, and the body language would slump.

Creative expression was evident in many of the activities the children discussed as being fun:

> "*Made a lot of stuff. I done a few pictures for the day ward downstairs...I did a lot of paintings as well...And I Made these plaster of paris's, like I made a dolphin, a dog, I gave a dolphin to my nana, a dog to my nana, and what else could you make?...a frog, a bull frog...It was real cool..." (Bill - 11 yrs, 2 mths)*

A range of creative mediums is used by Bill, with several of his artistic efforts being made for the enjoyment of others.

The activities in which the children were involved were nothing out of the ordinary, and could just as easily be observed in the home setting as in the hospital ward. The ability to do activities such as watch t.v. helped in retaining a semblance of normalcy to their daily lives. A key feature of these activities is the ability of the child to initiate them, and to a large extent, carry them out independently from parents and medical personnel. The fun and creative activities engaged in, therefore promoted a sense of control, independence and normalcy.

Becoming Familiar with the Physical Environment

Physical knowledge of the ward resulted in a greater choice of activities, and places to go.

> *"Um, we went sometimes, we went out to the café and we played, I played with the toys in the corner and mum had a cuppa……You get to, and there's this, eh when you go out, down the elevator there's this down, down the bottom there's this play area ... The doll's, yeah though that house ... the house, the play house and the horsey and all, and down there there's this um, train..." (Fairy - 6 yrs, 8 mths)*

Fairy in her talk about play describes two different areas of the hospital, both of which are off the ward, one being the Ronald McDonald Family Room, the other area is the playground downstairs that forms part of the waiting area in the outpatients clinic. Recall of the furnishings of the rooms, and their decoration, showed large distinction between children, and the furnishings appeared to serve different purposes.

> *"They's all covered with white walls." (Blah Blah - 8 yrs)*

This was the sum total of what Blah Blah remembered about the room, and it is significant in its impact on his memory in that he felt it important enough to describe what he had found uninteresting. Freeze, on the other hand, simply stated that there was nothing interesting in the room, without reference to its actual appearance. In contrast, Fairy liked her room and gave a very detailed account:

> *"It o, it was nice on the outside because they had these, it had this building around and it had this smiley faces on it...there was nice curtains as well...There were clown ones...With, with girl clowns and boys ...and some horses...And I got to pull it myself" (Fairy - 6 yrs, 8 mths)*

In this excerpt the furnishings provided a point of interest and a distraction, and were a source of pleasure. The final comment from Fairy is an example of having control over the environment, while also reflecting a perception of being trusted to pull the curtains. Interestingly none of the children, when asked, replied that they had placed their own artwork on the walls of their room, most replying that they had not in fact thought of it. This may be due to a sense of lack of control of the environment and therefore an inability to influence its appearance supported by the following extract:

> ***"Where are you going to put this picture when you've finished it?***
>
> *In my room.*
>
> ***In your room?***
>
> *I will make a rocket, already made.*
>
> ***And that's already up on your wall, is it?***
>
> *Yep... Want to see it?"(Chipmunk - 7 yrs, 4 mths)*

Chipmunk was busy throughout the interview creating a long mural picture, and had no hesitation in stating that it would go on the wall in his room at home, where other pieces he had drawn were already displayed. However, during his time in hospital he never placed any of his artwork on the wall. Fairy was also less than comfortable in her room, with the size of her bed rating a mention, on a par with vomiting, as part of her hospital experience.

> *"Um, awful... 'Cause you have to have needles... Um, and you vomit... And um, you had to um go on this big bed and have, have the needle in your portacath... And you had to lie on this big bed... In my room..." (Fairy - 6 yrs, 8 mths)*

The size of the bed was intimidating, and different to her bed at home. The bed dominates the hospital rooms and is the place children spend a great deal of time while on treatment. This seemingly harmless object took on, for Fairy, a threatening appearance, adding to the discomfort caused by procedures and being sick.

This physical environment was commonly seen as a source of status, reflected in the following description provided by Bill:

> *"Um, sometimes posters...Um... oh yeah glow in the dark stickers on the roof, yeah, and in the ensuite they had a bath, a shower...That was real cool." (Bill - 11 yrs, 2 mths)*

In Bill's own words it was 'real cool' having an ensuite, with an amount of status being accorded those whose rooms had one. There was further status attached to these rooms as they generally had their own television and video due to being used primarily for paediatric oncology patients needing isolation.

The schoolroom was used by all the children, but was central to the accounts of two participants. It represented both a place to go, and a source of activities and resources. Knowledge of its location and the range of resources available were important in determining the extent to which it was utilised as a place for play. Several of the participants made good use of the schoolroom and its facilities, while another used only the resources. For George the schoolroom was a central factor influencing his perception of the hospital. When asked what it was like going to school in hospital, he replied:

> *"Umm, it's more fun 'cause you can do anything you want...You don't even have to be there." (George - 8 yrs, 3 mths)*

George's comment contrasts regular school attendance with that at the hospital, and highlights the issue of control. His perception of being able to do whatever he wanted which he perceived as allowing him unlimited freedom, and corresponded to a lightening of his tone and manner when talking. Also, through the fact of attendance not being compulsory, George felt personal control over his movements. George also identified going to the hospital schoolroom as a good trade off for having to go in for blood tests. George was the only participant who had been treated at two different hospitals, with the above comments referring to his local paediatric ward. It was interesting to hear the difference in perspective when asked if going to the schoolroom at Wellington hospital was the same:

> *"No ... Cause you can't do what you want to do ... You have to do maths and stuff ... Stupid work" (George - 8 yrs, 3 mths)*

It is possible to see, with the loss of control over what he does, that George has a lowered motivation, and a negative attitude toward school attendance. This perception of the schoolroom in Wellington is influenced by the almost sole use of the schoolroom which George had at the local hospital. Other participants saw the schoolroom differently to George.

> *"go to the school room and do some work, play on the computers, send faxes to my classroom"(Bill - 11 yrs, 2 mths)*

> *"Umm, we went down to the, to the halls down, not downstairs, but round the corner ... We played on, we played on the computer ...And I, and I, and um, and um I got to play on the computer a little bit" (Fairy - 6 yrs, 8 mths)*

These participants describe a much freer environment then George, with a range of fun things to do. Part of the difference in perception may also be due to familiarity, as George spent less time in Wellington than the others. Chipmunk also showed a reluctance to go to the schoolroom, sending his mother to collect any resources he wanted. This may be a result of Chipmunk only being four years of age when first diagnosed, therefore school was an unknown quantity which he felt uncomfortable dealing with.

A disadvantage of the schoolroom was mentioned by Bill when talking about why some days were boring on the ward:

> *"Um, just school room closed over the weekends ... "(Bill - 11 yrs, 2 mths)*

For a normal child the weekends are typically the time for free activity, having been at school all week; for children with cancer their week may have consisted of treatments, confinement to bed, and isolation. Weekends free of isolation take on an added importance, where a closed schoolroom in combination with not being able to go home, leaves the child "all dressed up with nowhere to go", that is, they are primed for fun, but the primary environment for it is unavailable.

The gaining of knowledge of the physical environment included the availability of toys and resources. The presence of familiar toys brought from home was important to some participants, while others made little use of toys they brought with them. For example, Fairy on days when she wasn't feeling well, was able to play in bed with her 'doggy' that she had brought from home, while Freeze made no use of his Kennex set. Some participants were content to make use of games and toys available through the schoolroom. The novelty of some of these items served to gain the interest of the participants. Chipmunk reported his mum getting books from the schoolroom, and playing with a particular toy:

> *"we went to the school to get them...And toys!...We had a train set we got out...It was a wooden one...It never had a motor...we had to push it." (Chipmunk - 7 yrs, 4 mths)*

The majority of participants reported use of the computer, and Bill also used the fax. Being allowed to take games and toys out of the schoolroom was seen as an indication of trust, and allowed for their use when the schoolroom was closed for the day, or over the weekend. Having the toys in their own room encouraged greater exploration than if the child had only been able to access them in the schoolroom.

> *"...they had these little, in the classroom they had these little flat top computers and you could take them out...so I took one of those out a few nights...and they've all got different games and that..." (Bill - 11 yrs, 2 mths)*

Here Bill shows a knowledge of the resources available, the access that is allowed, and his exploration of the toy to discover the games available. Television and video were common toys used, with Wavy Gravy replying, when asked what was interesting in her room, "t.v., t.v., t.v.". It was of importance that the television and video be in the child's room, this imparted control over what was watched, and who watched, in addition to providing a degree of privacy:

> *"most of the days I did um, duh my boyfriend came he, we, I had the t.v. and we can watch it…That's all I watched: The Wiggles." (Wavy Gravy - 7 yrs, 6 mths)*

Here, Wavy Gravy was able to watch television in private with her boyfriend, and could watch The Wiggles continuously without needing to be concerned with the needs of others. In contrast, the television and video were not operational when Freeze was on the ward, consequently he found *"everything was boring"*.

Knowledge of the physical environment can be seen to be important for retaining a sense of normalcy for several reasons. Firstly, it lent an air of familiarity to the ward environment, and was indicative of the degree of exploration which was carried out, to varying degrees, by the children, and their attention to detail. This knowledge of the ward environment helped children define the limits of their control - what was controllable, (e.g., school attendance), and what was not, (e.g., schoolroom closed on weekends).

Secondly, children who had limited physical knowledge of the hospital, did not have the opportunity to explore different areas of that environment, nor did they have access to the different toys available, such as in the schoolroom. This limited their ability to explore and experiment with new objects. Thirdly, greater familiarity with the environment has a positive impact on feelings of independence, and self-confidence, as the unknown can be a source of unnecessary fear and uncertainty.

Gaining Knowledge of the Routines in the Hospital

Sleeping and eating were routines that gave a sense of normalcy to the hospital environment, although participants viewed them in comparison to home.

Various factors affected participants' ability to sleep, with the majority being treatment related.

> ***"What was it like sleeping in the hospital? Did you like that?***
>
> > *Umm, not so much... 'Cause ummm, nurses just come and wake you up to bring pricks ... Umm, it takes a while 'til I fall asleep." (Chipmunk – 7 yrs, 4 mths)*
> >
> > *"It's alright, if you're not ummm hung up to a drip 'cause they're really noisy." (George - 8 yrs, 3 mths)*
>
> ***"Did you find it easy to go to sleep?***
>
> > *(head shake)...The beds were uncomfy...Too soft, and I uhhh touch the umm, the bit underneath it, the metal bit." (Freeze - 8 yrs)*

Additional knowledge of the routines included information about the food available. As children during treatment often lose weight, having food that they will eat is important. The general consensus among participants was that the food, while sometimes okay, was less than ideal. The food that was rated as okay included items which appeal to the majority of children and don't normally constitute the total contents of a nutritious, well-balanced diet:

> *"I always couldn't eat any dinner, all I could really eat was fish and chips and ro, and roast things...Or McDonalds." (Wavy Gravy - 7 yrs, 6 mths)*

While some of the above items were available on the menu, they were not an everyday occurrence. Some of the food which was served up, described as only children can, included:

> *"Gross!...Yoghurts, coke, ...mashed potato and gravy...Boiled cabbage ...Gross stuff" (George - 8 yrs, 3 mths)*

> *"Um, this hard mince stuff one day...it was like rock, and mashed potato, sausages, just...but for lunch it didn't have um, fish and chips on the list but we could order fish and chips...So I ordered that...Not all, not every day...some of the days though." (Bill - 11 yrs, 2 mths)*

The last extract from Bill illustrates how 'insider' knowledge can make for a more pleasant experience. His awareness of the possibility of ordering items not on the menu offered him a choice, and a modicum of control over his life. Fairy's view of the food was focused on what she enjoyed:

> *"...if you're in hospital and you're sick you get free lunch...You get jelly and stuff...And you get, you get water melon and stuff like that." (Fairy - 6 yrs, 8 mths)*

This account reflects an understanding of the logical sequence of events, or the existence of cause and effect, that is, that in order to get a free lunch you had to be sick and in hospital.

Whilst sleeping and eating are activities in children's lives prior to hospitalisation, they were noted as being different in the hospital. The differences created uncertainty in some participants and discomfort for others whose sleep, ot eating patterns, were disrupted. The relatively uncontrollable nature of these differences in two central daily activities affects both the health and perceptions of the child. A lack of sleep can lead to negative appraisals of stressful situations and impact on the child's recovery rates from treatment. A reluctance to eat can create stress between parents and their child, while also compromising children's energy reserves and immune responses.

SUMMARY

The theme retaining a sense of self-as-normal comprised two main components interpreted from the behaviours and accounts of the children. These were: Maintaining links with familiar people, and Becoming at home in the hospital. The former involved parents, siblings, peers and school personnel and was important for maintaining a sense of stability in the world, and for perceiving the self as essentially unchanged. The latter component reflected efforts to familiarise oneself with the physical environment of the hospital ward, as well as the routines which guided life on the ward. Success in becoming at home led to greater confidence in exploring the environment; consequently increasing interactions, both with others and the environment. The following chapter describes the theme 'Incorporating multiple selves'.

CHAPTER SIX

INCORPORATING MULTIPLE SELVES

Our sense of who we are in the world (our self-concept), is not one large overall picture covering the entirety of our world. It is, rather, a picture made up of different definitions of ourselves and our value, in a range of situations over time (Ivey et al., 1997). In the same way the hospital experiences of children with cancer place them in different circumstances, in each of which they must make sense of themselves. The second theme, 'Incorporating multiple selves', is concerned with the children's efforts to define themselves in terms of the procedures, routines and people who form part of the hospital environment.

The central activities which occur in the hospital are those related to medical procedures and the treatment of cancer, therefore much of what follows relates to treatments. The accounts of the children revealed the different aspects of the experience which were salient, with individuals varying in the extent to which they were willing to describe their medical experiences in hospital. A pattern of responding emerged with some children being very articulate and willing to speak about whatever they could remember, while others made it quite clear that some treatment questions were off limits, and they would not even consider answering them.

The previous chapter focussed on the child's view of self-as-normal. In this chapter the meanings given to the participants' hospital experiences emerged as four perspectives: self-as-body-in-pain, self-as-confined, self-as-patient, and self-as-survivor-living-with-cancer. Each of these four views will be illustrated in the accounts of participants. The first three perspectives: self-as body-in-pain, self-as-confined, and self-as-patient, are situated in the past and relate to the children's time in hospital. They reflect the children's efforts to describe themselves in the new environment of the hospital. The last view of self-as-survivor-living-with-cancer, relates to the present time, and the children's living in the world. It represents the integration of the hospital experience into the self children present to the outside world. The extent to which children were able to balance the first three identities with a sense of self-as-normal, influenced the degree to which they formed a view of themselves as survivor.

SELF-AS-BODY-IN-PAIN

Pain and discomfort are unavoidable aspects of the hospital experiences for participants. This contributed to the view for all children of self-as-body-in-pain/discomfort. The pain was talked about in relation to pricks, while discomfort was discussed in relation to the physical consequences of treatment. Participants used a variety of coping responses to reduce pain and discomfort. The degree of perceived personal control influenced the choice of response utilised.

Pain from needles was a frequent comment, and was accepted quite matter-of-factly, as evidenced by the following descriptions of what it was like to have pricks or needles.

> *"Well it hurts" (Chipmunk - 7 yrs, 4 mths)*

> *"Um, painful" (Bill - 11 yrs, 2 mths)*

In fact the pricks were the worst part of being in hospital for Chipmunk, who saw no way to make them better, or easier to handle. The only behavioural response to the associated pain of pricks was crying, reported by only two of the participants. One of those participants viewed crying as a negative behaviour to be controlled.

> ***"So you liked all the pricks and medicine and…?***
>
> *No…You liked them, hah hah.*
>
> ***I liked them? I haven't had any.***
>
> *Yes, you did. And you were crying.*
>
> ***And I was crying, oh. That's okay to cry isn't it?***
>
> *No it isn't.*
>
> ***It isn't?***
>
> *If you cry you don't get a lolly." (Blah Blah - 8 yrs)*

Blah Blah was unwilling on the whole to discuss the hospital at all, and this was one of only two responses made to questions regarding his hospital experiences. A notable feature of this exchange is the manner in which Blah Blah avoids discussing having pricks by changing the pronoun, thereby distancing himself from the situation. The content of the extract clearly shows that Blah Blah perceived crying to be a behaviour which resulted in the negative consequence of no lollies, therefore making it necessary to control such behaviour. Acting inappropriately was seen as not okay, and reflected on the person as much as the behaviour. In contrast, Chipmunk also said that he cried 'a little bit' when having pricks, but had no perception of negative consequences. He was still able to pick something from the basket of goodies after having pricks.

One participant found a pharmacologic intervention helped with the pain.

> *"...getting needles but I don't care about needles anymore 'cause [doctor] gives me this special cream." (Wavy Gravy - 7 yrs, 6 mths)*

Getting needles was one of the worst things about being in hospital for Wavy Gravy, but less of a concern with the use of the special cream - EMLA - which is an anesthetic (Ellis & Spanos, 1994). Wavy Gravy also coped with much of her treatment by sleeping.

Another participant developed her own way of dealing with pricks.

> *"No, ... all I do is go like this. (Closes her eyes and holds herself tense).*
>
> ***You just close your eyes?***
>
> *Yeah. (Very matter of fact)... Yeah, and it doesn't even hurt...They got the needle, and then, and when they put the needle in they just go like that. And it just, it just um doesn't even hurt." (Fairy - 6 yrs, 8 mths)*

This method of bracing herself was successful in coping with pain associated with the relatively quick procedure of inserting needles into her portacath, but not for the presence of a needle in the back of her hand after surgery. This needle was unwelcome 'because it hurts', both during the period after surgery and after its removal. Although Fairy states that needles don't hurt, she still included having needles into her portacath as an awful part of being in hospital, indicating that the pain of the actual procedure may not be the only influence in her perception of unpleasantness. Anticipatory anxiety, and the memory of previous painful experiences may play a part in Fairy's dislike of needles. Expectations from others of appropriate behaviour may have a part to play also. This is shown in the following comments:

> *"And I've been brave all through it...Yeah when I had, when I had needles..." (Fairy - 6 yrs, 8 mths)*
>
> *"...I had bloods done a lot...I got used to needles after a while." (Bill - 11 yrs, 2 mths)*

These indications of habituation to needles, which came through some of the participants' accounts, were often contradicted with later comments. It may be that the participants are responding to expectations of others. This may be particularly of relevance in Fairy's case as bravery is not a characteristic children naturally aspire to, but is rather a concept introduced by adults. It is also possible, due to the retrospective nature of their reports, that participants have forgotten some of the impact of needles and pricks.

Chemotherapy was not spontaneously raised by any of the participants, and related comments described the physical consequences such as vomiting. Participants differed in their ability to find things that would help them cope with the unpleasantness of the experience, including peer support and pharmacologic means.

George found talking about chemotherapy uncomfortable, and would continually focus on the schoolroom. Chipmunk gave no response to an initial question about chemotherapy, and was quick to interrupt a further question, saying he didn't remember what it was like. His body language was tense and his tone of voice abrupt, clearly signaling a desire to move on. Later in the interview he did comment on the medicine and pills:

> "***Was the medicine and the pills alright?***
>
> > *Umm, the medicine wasn't but the pills were...The medicine wasn't...'Cause it tastes disgusting" (Chipmunk - 7 yrs, 4 mths)*

The medicine also made Chipmunk feel sick, which necessitated a pill to make him feel better. Sometimes the pill didn't work in reducing the discomfort, in these cases Chipmunk was unable to describe any alternative ways that he used to cope. Fairy also used pharmacologic means to cope with the consequences of chemotherapy, which in her case was vomiting. Wavy Gravy used both pharmacologic means and peer support to help her cope with feeling nauseous. She also found that the medicine didn't always help, but knowing that burping preceded vomiting helped her in having a sense of predictability and control.

> "***What was it like having chemo?***
>
> > *Uhh, sicky...But I didn't care, 'cause they gave me sicky pills.*
>
> ***Did they work?***
>
> > *(nod)...But not all the time I had one...but sometimes I always get a cold at night when I go into the bathroom I mean go to toilet and then go to bathroom to wash my hands and then I go back to toilet and I spew up...and keep doing that each night, no, not each night but like every time that ...*
>
> ***What's it like being sick all the time?***
>
> > *Hmm, feels I just...I know when I'm going to be sick because I burp first...And that helps me a lot." (Wavy Gravy - 7 yrs, 6 mths)*

Wavy Gravy spoke of the role of peer support in making her feel better, while also indicating that interaction depended to a large extent on who was feeling well that day, so that feeling unwell meant you were less likely to want to initiate contact, but that contact was nonetheless welcome as a distraction. The presence of a friend was a source of comfort, and reassurance, and helped make her feel better.

> *"... 'cause some days, some of my, like [friend], they, she would come in if she was feeling well and read me a book or something if I was feeling sick and she would feel well." (Wavy Gravy - 7 yrs, 6 mths)*

Only one participant spoke of his emotional response to chemotherapy; his coping strategy was also to seek peer support.

> *"Yip, I had that for about a year? (asking mother)...yeah, eight and a half months...and I had to go in every Wednesday and stay the night.*
>
> ***How did that make you feel?***
>
> *Um, sad sometimes, but I sent faxes to my class a lot...Sent a real as long one." (Bill - 11 yrs, 2 mths)*

Sending faxes to his class also served as a distraction from Bill's feelings of sadness, and helped to reinforce his bond with classmates. Further, as discussed in the previous chapter, contact with friends made prior to diagnosis, helps to maintain a sense of self-as-normal and therefore essentially unchanged. Social support provides Bill with a sense of stability, and a link to the future in his hope of returning to school and his friends.

Self-as-body-in-pain places pain and discomfort within the confines of treatments and procedures. This containing of pain, and relating it to specific situations in which it occurs, reduces its sphere of influence, portraying a less pervasive perspective. Having knowledge as to the link between pain/discomfort and procedures aids in coping as pain can not be anticipated, and coping responses prepared. For example, Wavy Gravy can ask for the 'special cream' prior to having needles in the future.

Knowing, or the children's perceptions of, the expectations of others regarding appropriate coping responses can be both hindrance and help. It was hindrance in Blah Blah's case as he found it difficult to meet the expectations. Fairy, in contrast, felt pride in successfully meeting expectations of bravery.

SELF-AS-CONFINED

A common experience among participants was the need to comply with rules regarding treatment. This involved at different times isolation, confinement to bed, the restriction of movement, and separation from parents. The need for compliance invariably resulted in children feeling confined, with little ability to influence the course of events.

Isolation is sometimes necessary due to the depression of children's immune systems as a direct result of having cancer or because of treatments, and their subsequent vulnerability to infections. The language used to describe being unable to leave the room was often quite graphic in its depiction of a lack of control, as evidenced by Bill in his description of the worst thing about being in hospital.

> *"Um, ...Locked in my bedroom... Low platelets" (Bill - 11 yrs, 2 mths)*

Bill understands that he is in isolation due to low platelets, and the need to guard against infection, a situation over which he has no control. In this example, use of the word 'locked' indicates a strong sense of being unable to influence the ability to come and go freely, while also implying that someone on the 'outside' has the key.

Ill-health and treatments sometimes necessitated temporary restriction of movement, for example, during chemotherapy. Being released from this confinement seemed of great importance to the majority of participants and signaled physical freedom. It also represented regaining a sense of control, as many of the children talked in terms of being 'allowed' out of their bed or room, indicating a lack of choice previously.

> *"Yeah, and when I was, when I didn't have a bag when I had the drip taken off when I was allowed the drip off for a um, a while, I used to play in the wheelchairs go up and down the corridor in the wheelchairs, we'd have races, me and my friend." (Bill - 11 yrs, 2 mths)*

In this extract Bill talks about being allowed physical release from the drip, and the freedom it provides for him to move about. The lack of choice regarding being confined to bed was also a factor in the mood of the children, as illustrated by George in his response to being asked what he wants to be doing when he's bored.

> *"Go outside...When it's raining I'm okay, umm and I'm not allowed outside, I'm okay, when it's sunny and I'm inside, I'm not allowed outside - I'm angry." (George - 8 yrs, 3 mths)*

Other discussions of procedures and treatments centred around Hickman lines, portacaths, tubes and drips. Four of the children had Hickman lines and the topic which emerged as the most vital for three participants was the inability to go swimming.

> *"Some of my other friends they had portocaths, and they could swim and that...but I couldn't, I couldn't have a bath, or I had a little baths..." (Bill - 11 yrs, 2 mths)*
>
> *"Stink!...Couldn't go swimming...Um, couldn't have big fights." (Freeze - 8 yrs)*

The exclusion of full contact activities was a further restriction for Freeze, who liked to play rough with his friends, and found it annoying to have tubes hanging around. Bill commented that sometimes his Hickman would get pulled causing considerable pain. Chipmunk did not like his Hickman.

> ***"Do you remember if you had a Hickman line?***
>
> > *Umm, not so much...Was a very long time ago...And I didn't want one...I'd rather get pricks.*
>
> ***Why didn't you want one? Do you remember?***
>
> > *I didn't like them.*
>
> ***Yeah. You didn't like the way they looked, or...***
>
> > *I didn't like them.*
>
> ***So did you have one for a little while, then?***
>
> > *Yep. Meant couldn't go for a swim." (Chipmunk - 7 yrs, 4 mths)*

Hickman line infections were a common source of difficulties, necessitating hospitalisation due to the line being direct to the heart. Chipmunk's experience with his Hickman was very unpleasant with two occasions of being hospitalised with infections in his line, even though he was reluctant to speak about these times. It is indicative of the trauma associated with his Hickman that even though Chipmunk thought having pricks was the worst thing about being in hospital, he still felt it would have been better having pricks than having a Hickman.

An infection was the source of Bill's anger on one occasion.

> *"being in there for so long. I had a, a bug in my line, in my lumens and I was in there for two weeks. I had to ...(correction from mother)...three weeks, and we had to go in there 'cause my, I went home my temperature was bursting and we had to go in at about 3 o'clock, me and mum." (Bill - 11 yrs, 2 mths)*

Bill vented his anger by throwing pillows at people, or just around the room. Chipmunk gave no indication of either his feelings in response to his difficulties with the Hickman, or how he coped. Wavy Gravy also had a Hickman and coped by giving her lines names, making them more familiar, and giving her ownership and control over some aspect of the treatment.

Those children who had portacaths seemed to have no problems with either restriction of activity, or infections. The only disadvantage was having to be pricked. George called his portacath an 'extra booby', grinning while saying it. This relaxed mood dissipated when asked if it was a cool thing to show friends, to which he replied in the negative. He also reported some pain and discomfort related to the portacath. Fairy was unconcerned with her portacath:

> *"Um...Just feels normal...Forget about it...Doesn't hurt."*
> *(Fairy - 6 yrs, 8 mths)*

Bill used humour, in addition to redefining the use of the equipment from hindrance to mode of transport, to help him cope with the restriction caused by being hooked up to I.V. poles.

> *"...sometimes quite hard to walk 'round sometimes I used the trolley as a scooter (grin on his face)...It was quite fun...(laugh) sometimes I had ah, um...yeah, and sometimes I had two uh trolleys to wheel 'round." (Bill - 11 yrs, 2 mths)*

The device Wavy Gravy found more difficult to handle physically than the Hickman, was the nasal-gastric tube.

> *"I hated the one I hated was this one up my nose...Yeah, it felt funny when I was going in and I couldn't laugh... And it hurt as well around here and there (pointing to places)." (Wavy Gravy - 7 yrs, 6 mths)*

An experience shared by the majority of participants was surgery, which was seen as difficult by some due to the separation from parents. This separation was interpreted by me as confinement due to control of parental presence being exerted from outside of the child's control. Surgery rated as the worst treatment for Fairy because her mother wasn't there with her throughout the procedure. Her mother was with her up until the time she fell asleep, but the knowledge of her mother's absence was sufficient to induce fear.

> ***"Can you tell me why** [you don't like surgery]**?***
>
> *It was, when, when I, when they took me asleep, mum goes.*
>
> ***Oh, right, you don't like it when mum goes, when they put you to sleep?***
>
> *(head shake)" (Fairy - 6 yrs, 8 mths)*

The dislike of surgery was compounded by her mother also not being there when she woke up, and having an unfamiliar nurse there instead. The unfamiliar room and personnel made Fairy feel 'sad', which she felt would be helped by the presence of her mother when she woke up. There were however, some 'fun' experiences associated with surgery for Fairy because she likes riding elevators and after surgery 'you get to go in a lift in a bed'. Freeze said surgery was 'boring', but was reluctant to talk about it further, appearing tense and unhappy, apart from stating that either his mother or father went with him. George was unconcerned about going into surgery, commenting instead on what it felt like coming out of the anesthetic:

> *"Crooked...Like lying in bed ...for a long time...My legs had gone to sleep" (George - 8 yrs, 3 mths)*

A lack of control over his body after surgery was a curious experience, rather than a fearful one for George. Wavy Gravy experienced some distress prior to the anaesthetic taking effect, and used quite graphic language to describe the proposed operation.

> *"Bit, um, well when they were gonna, when they were gonna cut my tummy open uh, I started crying but then I fell asleep 'cause of the sleeping medicine...But it smells yuk." (Wavy Gravy - 7 yrs, 6 mths)*

Wavy Gravy was also very aware of the presence/absence of her parents, remembering that they were not there prior to surgery, but that her father took her back to her room after surgery.

This perspective of self-as-confined was also reflected in the comments which matter-of-factly recounted side-effects, indicating a lack of control, and in the children's tendency to gloss over talk of treatment in favour of recounting a positive event, or receipt of a gift, which immediately followed treatment. The treatments were carried out on the self-as-patient, while the recipient of the surprise event or gift was the self-as-normal. The experience of radiation was mentioned by only one participant, Bill, who stated the physical consequences very matter-of-factly.

> *"...I had radiation for about three weeks.*
>
> ***What was that like?***

> *Um, quite hard, it killed my spleen, and the top of my kidney... Um, but after my radiotherapy I met Filo Tiatia [and some others whose names I can't spell - league players I think]...and I forgot, and I got to answer their cell phones...*
>
> ***And how did the radiotherapy make you feel?***
>
> *Um, sick sometimes and dizzy." (Bill - 11 yrs, 2 mths)*

This excerpt reflects a common pattern of glossing over talk of treatment in favour of a discussion about positive events, or the receipt of treats, which followed closely behind an unpleasant procedure, or period of illness. Wavy Gravy spoke at length about several surprise events and gifts which served as distractions from the memory of unpleasant hospital stays.

> "***What was it about the tubes that you didn't like?***
>
> *Uuummm, um they hurt...I don't care 'cause I always fell asleep anyway. And I've got a big doggy on my, under my bed from daddy's work saying: I miss you Wavy Gravy - 7 yrs, 6 mths, 'cause I haven't seen you for ages. Here's a present from your dad and all the folks at, at dad's work...But dad buyed it ..." (Wavy Gravy - 7 yrs, 6 mths)*

Talk about an unpleasant experience - having tubes - is quickly sidestepped with the introduction of talk about a gift. Children showed very good memories when recalling gifts received, while apparently being unable to remember much about the treatment which immediately preceded receipt of the gift.

Self-as-confined reflects children's perceptions of themselves as bodies controlled by external factors. The children's accounts illustrate the lack of control they feel over their body's functioning. The view of self-as-confined works to interrupt the perception of self-as-normal, seriously challenging the stability of their self-image, particularly in terms of their body. Their body image requires adjustment as they now have tubes or an 'extra booby', which sets them apart from both what they looked like prior to diagnosis, and what their peers look like. Humour, and glossing over treatment in favour of discussing a pleasant event, were used as coping responses. These seemed of some benefit for minor confinements but, overall, 'self-as-confined' was an unhappy, frustrated person, who endured circumstances, rather than coped.

SELF-AS-PATIENT

Self-as-patient emerged from the interactions with doctors and nurses. It describes the degree to which the children were able to develop social relations with the personnel most involved in their care. There was a lack of intimate interaction between participants and doctors, while relationships between participants and nurses varied in their degree of intimacy.

Very little response was elicited from participants, positive or negative, when discussing their relationships with doctors. The interactions reported appeared very impersonal. None of the children reported asking the doctor any questions about their treatment, although the older children reported feeling confident in speaking to the doctors. Only a few remembered the doctor explaining the treatment they received. Some children knew the name of the paediatric oncologist responsible for their care, and had tracked his movements, implying that a bond had existed.

Bill was the only participant to both express a preference for a particular doctor, and recall an interaction which went beyond the medical. When asked what the doctors were like, Bill replied:

> *"Um, they're nice. I had a neat ..., uh doctor..., but he went back to England...and he was cool but, and a lot of CT scans they injected the dye too fast and it made the canula just explode...Whoost, kebang, and then [preferred doctor], I'd only let [doctor] do it 'cause he did it nice and slowly...and there was no problems when [doctor] did it, but when the people in CT done it, it sometimes went all over the place...But now they're gentle." (Bill - 11 yrs, 2 mths)*

Not only does Bill express a preference for a particular doctor, but he also gives very good reason for his preference. Trusting the doctor was important to his ease with the procedure. Bill mentioned the following incident during his discussion of having radiotherapy.

> *"Yip, and um when I was waiting for radiotherapy um I got a plaster of Paris of my hand made, and it's up on the fridge...And, 'cause I had to wait for ages, and the doctor said I could go and make, make one with him, so we made one, and um, it broke, one of the fingers broke...But, oh well." (Bill - 11 yrs, 2 mths)*

The interaction between the doctor and Bill serves to distract Bill from the long wait associated with having radiotherapy. The activity was also an enjoyable and creative effort which was seen as worth keeping. Bill shows a philosophical attitude to the breakage of the finger, which was also evident in his overall attitude to cancer and its treatments.

The view of self-as-patient prompted the use of distraction and ignoring as coping responses. There was a marked reluctance to discuss treatments that were carried out on the self-as-patient, and attention was diverted to events involving the self-as-normal. This may be further evidence of an avoidant style when dealing with distressing procedures. It may also reflect the child's monitoring of the image portrayed to the interviewer.

Children, in their efforts to create social ties within the hospital environment, made appropriate use of medical terms, gained knowledge of treatments, learned to carry out some of their own treatments, and expressed what helped them to cope. In the previous section, Bill's account of C.T. scans illustrates the use of medical terms as well as stating what helped him cope - namely trusting the doctor who carried out the injection of dye.

> ***"And did you know what was happening in the operation? Did the doctors come and tell you about what they were going to do? Did mummy or daddy tell you about what was going to happen?***
>
> *(head shake)...I knew myself.*
>
> ***How do you think you found out what was going to happen?***
>
> *Um, because my last one where they cut my tummy open they, they they've already done it so they just have to cut my tummy open again and that's the room I went in, so I remembered...It was the, it was that line there that got cut, there when I (showing me her scars)...That's where I got my tumour out, I mean my tube out...My tubour, my scar's there from my tumour, to get, to get my tumour out." (Wavy Gravy - 7 yrs, 6 mths)*

In this extract Wavy Gravy explains her knowledge as resulting from memory of a previous surgical experience. She also illustrates knowledge of her body and the cause of her scars.

Children's coping differed according to the nature of the interaction they reported with nurses. Talk regarding nurses centred around what they did which was helpful in coping with the hospital experiences, and what made coping difficult. The following accounts illustrate children's ability as experts on themselves, to describe interactions which supported their coping efforts.

Most of the children named at least one of their nurses, and the majority were able to describe what they were like, and why. Knowing the nurses on the ward came through as being important, this is possibly due to familiarity imparting a sense of security, and continuity. In the following exchange George is very definite in his preference for having nurses that he knows working on him.

> ***"What are the nurses like?***
>
> *Umm, some of them are good.*
>
> ***What is it that they do that's good?***
>
> *I know them.*

> ***That makes things better for you? Are there things that they do with you?***
>
> *Yep...Play with me... Cards, ...*
>
> ***What about the other nurses, the ones you don't like so much?***
>
> *I don't like them...I'm not used to those nurses.*
>
> ***You're not used to those nurses. Are they nurses that aren't on the ward all the time?***
>
> *Yes.*
>
> ***What do you think they could do to help make you feel more comfortable?***
>
> *Get someone I know to do it.*
>
> ***What about if they can't get someone you know to do it? How can the new nurses, the ones you don't know, how can they..***
>
> *Don't do anything.*
>
> ***Do you think if they played games with you too it would help?***
>
> *Na.*
>
> ***You just like to have the nurses that you know?***
>
> *Yeah." (George - 8 yrs, 3 mths)*

George indicates implicitly that the degree to which a nurse is known will influence the degree of acceptance the nurse receives when interacting with the child. It is unclear from George's account quite how a new nurse would go about being accepted, or why being known is important. We could assume that being known has an element of trust inherent in it, as regular contact may have proven their ability to treat the child with care. This extract underlines the importance of having familiar people around the children, and that staff changes can cause unease and non-compliance with procedures.

In general, paediatric oncology patients are assigned a nurse which facilitates familiarity. Having a familiar nurse has important implications for procedures such as surgery. It may aid recovery and quickly reassure a child if a nurse they are familiar with, attends to them in the recovery room. It may also be reassuring when a child comes into hospital unexpectedly. Both Bill and Wavy Gravy talk about their favourite nurses being there when they have to come in because they are sick.

> *"I haven't seen, um ah there was, there's one called [nurse] and we always came in when I was sick when she was um the, when she was um, when she was the nurse to me...And the, and she always came in and telled me some jokes or something..." (Wavy Gravy - 7 yrs, 6 mths)*

> *"And [nurse], when me and mum had to go in about three o'clock in the morning [preferred nurse] was my nurse..." (Bill - 11 yrs, 2 mths)*

Interaction with nurses was the topic of much of Bill's interview. The following incident is representative of the relaxed, informal nature of Bill's relationship with some of the nurses. This relaxed interaction seemed to place Bill on an equal level with the nurse, and the interaction is similar to that between friends.

> *"Sometimes, we couldn't get any through and a nurse betted me and my line was blocked and she betted me that we'll get blood out and I said we won't 'cause it was so blocked, and she said if I get it wrong I have to buy her a chocolate fish and then if I get it wrong I have to buy you on, and I got it right so she had to buy me a chocolate fish...(laugh)" (Bill - 11 yrs, 2 mths)*

The friendly nature of his relationships with some of the nurses was also a source of disappointment, as the boundary between nurse and friend is a fine one, which is difficult for children to understand. An example is when Bill saw the Harley belonging to his favourite nurse, but the nurse wouldn't take him for a ride on it, his reaction was of disappointment but also of resentment and having been let down. Also children often take practical jokes beyond the limit, provoking a reaction that may not be expected, and damaging the bond between nurse and child. In the following example Bill found the nurse's reaction amusing, another child may have been very upset by it.

> *"[preferred nurse]... he loved his 'V' ...and I was the first one to the trolley and I got his 'V'...(laugh)... and he was angry with me (still chuckling)..." (Bill - 11 yrs, 2 mths)*

Bill also mentions knowing the nurses, although he does not exhibit the same rejection of new nurses as George.

> *"Ah, I met a lot of nurses...after I came out I met practically every single one but now I go in there's new nurses...Yeah. Some of them have left...Yeah." (Bill - 11 yrs, 2 mths)*

The relative unconcern with new nurses may be due to the fact that Bill now only goes to the hospital for check-ups, so the interaction between him and the nurses is not as intimate as when on the ward.

Another aspect of Bill's interactions with the nurses was feeling useful.

> *"...I used to do some work for the nurses.*
>
> ***What sort of work did you do?***
>
> *Um, stamp envelopes, fold envelopes, put stuff in them, um...write the date on stuff...*
>
> ***Did you enjoy doing that?***
>
> *Yeah...Yeah, I used to do my own blood pressure (chuckle)...I know how to do that..." (Bill - 11 yrs, 2 mths)*

Here Bill also gives an example of taking control of a regular part of his health care; this required the nurse's permission. Chipmunk's memory of the nurses relates to their intrusion into his room, and giving pricks.

> ***"Was it noisy at night?***
>
> *Ummm, yep... 'Cause ummm, nurses just come and wake you up to bring pricks." (Chipmunk - 7 yrs, 4 mths)*

Chipmunk did, however, show knowledge of the nurses role.

> *"**What do you think the nurses were there to do?***

> *Umm, to make me better.*
>
> ***How do you think they did that?***
>
> *By giving me medicines and pills.*
>
> ***Are there any other things they did that maybe helped to make you feel better?***
>
> *Umm, forgot. Umm, when we get pricks.*
>
> ***Did it make you feel better at the time?***
>
> *(Banging pencil) Umm, not so much." (Chipmunk - 7 yrs, 4 mths)*

He was aware of their role but it didn't mean he liked what they did! Later, when responding to a question about whether he would want anyone to sleep with him at night apart from his mum, he implicitly states that nurses are strangers.

> *"Hmm, no... 'cause then it would be noisier... with my dog it would be very noisy... the nurse would just walk past and he would go "woof, woof"*
>
> ***Does your dog bark a lot does he?***
>
> *At strangers... We're not strangers to him." (Chipmunk - 7 yrs, 4 mths)*

Chipmunk differentiates between he and his mum as 'insiders', and the nurses as 'outsiders', strangers to be wary of. Later in the interview, when discussing what he would take to hospital if he had to go back, Chipmunk made the following comment:

> *"Maybe my, our dog. That would scare all the nurses away.*
>
> ***Do you want someone to scare all the nurses away?***
>
> *If they keep, they won't keep on waking us up... But then our dog will wake us up... (mumble)" (Chipmunk - 7 yrs, 4 mths)*

Chipmunk shows a desire to cut off or control the interactions between himself and the nurses. This is not surprising when, as we see later, Chipmunk sees a primary role of the nurse as giving pricks, which just happens to be one of the worst things about being hospital for him. Chipmunk gives no examples of pleasant interactions with the nurses, nor does he mention any of their names.

In Bill's case, nurses were seen as important sources of fun activities, with one nurse being favoured above the rest.

> *"The favourite one was [nurse], and we played noughts and crosses, and I've still got one on my arm just there." (Bill - 11 yrs, 2 mths)*

This nurse as mentioned earlier was also the source of syringes used to squirt water at staff and family alike. Bill's account contained numerous references to this nurse, and each incident was described as fun.

Part of the familiarity of nurses was having a knowledge of their role. There was a general consensus when asked, that the nurse was there to make them feel better either by giving medicine or pills.

> ***"What happened when you were not feeling very well?***
>
> *Umm, the nurse came .*
>
> ***And what did she do?***
>
> *Umm, make me feel better.*
>
> ***How did she do that?***
>
> *Umm, by giving me a pill." (Chipmunk - 7 yrs, 4 mths)*

Answering the buzzer seemed to be a primary task as perceived by the children.

> *"...And it was nice because when you're lying in bed and you want something you just press the buzzer and they come in and say "what do you want?"*
>
> ***Oh, who comes in?***
>
> *The lady...And they get you what you want.*
>
> ***Do they always get you what you want?***
>
> *Hmm.*
>
> ***And do they come quickly when you press the buzzer?***

> *No, they just walk.... 'cause they're not allowed to run...And I was upstairs in ward 18." (Fairy - 6 yrs, 8 mths)*

George saw the buzzer as a great toy, but was annoyed on the following occasion.

> ***"What about when you're on the ward and say Mum's gone out for a while and you need something and you can't get it for yourself?***
>
> *Buzzer!*
>
> ***What's it like when you ring the buzzer?***
>
> *Nurses come*
>
> ***And what do they do?***
>
> *Whatever you want*
>
> ***And has there ever been a time when they haven't come when you wanted them to?***
>
> *Yeah*
>
> ***What happened then?***
>
> *I peed in my pants*
>
> ***How did that make you feel?***
>
> *I don't know*
>
> ***How did you feel towards the nurses?***
>
> *Well, you should come*
>
> ***Did they come afterwards, did they?***
>
> *Yeah, they came before, ...they came after I peed my pants*
>
> ***And did you say anything to them?***
>
> *No*
>
> ***Did they say anything to you about why they didn't come when you buzzed?***
>
> *(shake of head)*
>
> ***How did that make you feel?***
>
> *It was alright." (George - 8 yrs, 3 mths)*

There are several points of interest in this exchange, one is that even though George was annoyed that they hadn't come in time for him to go to the toilet, he said nothing to the nurse. Secondly, it is interesting to note that he doesn't remember the nurse saying anything to him either. Finally, although he says that it was 'alright', his body language was withdrawn and his tone subdued.

Most participants differentiated between 'good' and 'bad' nurses, often naming examples of each. Generally, however, participants were unable to describe what specifically they liked or disliked about particular nurses.

> *"There was [unpopular nurse], I didn't like her much.*
>
> ***What didn't you like about her?***
>
> *[nurse] was my best, oh the first nurse I ever had when I was admitted... Yip. But sometimes I would have [unpopular nurse] in the night and she would come in and change, mum and dad wouldn't tell me... They were sneaky... They wouldn't tell me" (Bill - 11 yrs, 2 mths)*

Bill dislikes one of the nurses, but declines to comment why. The fact that his parents don't tell him when the unpopular nurse is on duty is perhaps indicative of the strength of his feelings. It may be that his knowing would negatively impact his mood, or cooperation with treatments.

Freeze was the only participant who was able to provide an indication of why particular nurses were disliked, although on further questioning he was unable to clarify what behaviours were 'rough'.

> ***"What about the nurses what were they like?***
>
> *They're okay.*
>
> ***All of them were okay?***
>
> *(head shake)*
>
> ***What did the ones who weren't okay, what were they like?***
>
> *Umm, I don't know... rough." (Freeze - 8 yrs)*

The reasons for liking nurses varied.

> *"**Why is she your favourite?***
>
> *'Cause...she's got long hair...And, and she's tall...Ah, short... Yeah, and um she does, does some things for me and stuff like that.*
>
> ***What things does she do with you?***
>
> *She likes (mumble)... She likes me.*
>
> ***How do you know she likes you?***
>
> *'Cause she saw me when I was in hospital." (Fairy - 6 yrs, 8 mths)*

> ***What did she do that was nice?***
>
> *'cause if my mum was out there I, I was asking where my mummy was and she would come and see...and I would ring the buzzer and she would always come and ask what the matter was." (Wavy Gravy - 7 yrs, 6 mths)*

Children had a view of self-as-patient which was specific to their own body, and their experiences in the hospital. This view contained a perception of expertise which lay in knowing their personal likes and dislikes, and recognising what was helpful in coping with the hospital experience in general. The single most influential factor on children's coping was their relationship with the nurses. Relationships based on personal interchanges, mutual liking and trust resulted in better adjustment, interpreted from children's willingness to discuss their times in hospital, and the general tone of their accounts.

The relationships with nurses which were personal in nature provided support for the child, by focussing on the self-as-normal, rather than the self-as-body-in-pain, or self-as-patient. The interactions which formed part of these personal relationships were similar to those carried out with family and friends. Furthermore, the support provided by relationships with nurses, based as they were on mutual trust, imparted control to the children, even if only over small aspects of their experience such as Bill taking his own blood pressure.

SELF-AS-SURVIVOR-LIVING-WITH-CANCER

This perspective contained two relatively distinct aspects. The first aspect of this view of self, emerged in the accounts of only two participants in their referral to the deaths of children from the ward. Implicit in these descriptions is the view of themselves as survivors, but still living with the threat of death.

> ***"So you made lots of friends in hospital?***
>
> *Yip...But, um, one of them's only just, one of thems lived and the rest have died...And that's four?(looking to mother for confirmation)*
>
> ***How does that feel when they...***
>
> *Umm, pretty sad.*
>
> ***Were you in hospital at the same time when they died, or..?***
>
> *Nah...I went to all of their frunrals, funerals.*
>
> ***Said your goodbyes.***
>
> *Yip." (Bill - 11 yrs, 2 mths)*

> *" .....'cause my um friend ..., the one that died...Me and [friend] were the only ones really playing with each other...We were best friends and I went to [friend's] funeral...It was sad...But I don't care because I saw her body.*
>
> ***That make it easier for you?***
>
> *(nod)*
>
> ***You said goodbye?***
>
> *By giving her flowers." (Wavy Gravy - 7 yrs, 6 mths)*

The reality of death is acknowledged, and implicit within these extracts is the possibility of their own death. This is in contrast to the common belief in childhood of a sense of immortality, or that only old people die. The spontaneous discussion of the deaths of these friends, indicates the importance placed on both their friendship, and their dying. It appeared to be important to achieve closure in some way with those who had died, either through viewing of the body or attendance at the funeral. This may be a way of highlighting their survival for themselves.

Bill also refers to himself as a survivor when he places his cancer experience in the same view of himself as having survived another life-threatening event.

> *"...I had a first needle when I was about four, when I got run over... Yip. So, I haven't only just had cancer, I've been run over as well..." (Bill - 11 yrs, 2 mths)*

The second aspect of self-as-survivor-living-with-cancer was apparent in the majority of accounts and related to survival being reflected by freedom from hospitalisation, while the cancer experience was ongoing in nature, due to the need for outpatient treatment and regular check-ups.

> *"I didn't have to go to pricks when I was in the hospital, but umm I had to go to pricks when I'm home, I can stay home when a little bit better...I get to go home but they wanted you quite well to ..." (Chipmunk - 7 yrs, 4 mths)*

Chipmunk's excerpt recalls going back into the hospital for treatment, and that it was only when he was 'quite well' that he was allowed home. Implicit in this description is the notion of survival.

The ongoing nature of cancer and its effects were evident for Wavy Gravy. Although her Hickman caused no major medical problems, Wavy Gravy gave the following response when asked if there was anything she didn't like about having it:

> *"...some people asking me why I've got a Hickman, what, why did you name them? ...And I hate people asking me about why do I have those splints on my legs...I just walk away and don't listen...I don't like people asking that." (Wavy Gravy - 7 yrs, 6 mths)*

Social anxiety is evidenced in Wavy Gravy's concern regarding other people's curiosity, and reflects a sense of being different from others.

The self-as-survivor-living-with-cancer is possible because all the participants have completed treatment, are at home when interviewed, and are alive. It is doubtful whether accounts of hospital experiences elicited from currently hospitalised children with cancer, would reveal this perception of self. This view may thus reflect elapsed time since last treatment, and the gradual development of perspective. Recognition of self-as-survivor is important in order for the children to celebrate survival and not feel guilty about it. Celebrating survival enables the children to be the self-living-with-cancer. Neither Bill nor Wavy Gravy present any evidence of guilt at having survived. Their saying of good-bye to their friends is interpreted as a tribute to their value, without any questioning of their own survival. There is, however, a recognition of death as a possibility, but this is not dwelt on.

SUMMARY

Incorporating multiple selves requires the balancing of self-as-normal, with the identities of self-as-body-in-pain, self-as-confined, and self-as-patient. The ultimate goal is to emerge from the paediatric oncology experience with a sense of self-as-survivor-living-with-cancer. Chapters Five and Six have explored the themes of Retaining a sense of self-as-normal, and Incorporating multiple selves. In Chapter Seven some of the implications of these themes for children with cancer coping with their hospital experiences, will be discussed.

CHAPTER SEVEN

DISCUSSION

The purpose of this study was to examine the hospital experiences of children with cancer to gain some understanding of ways in which they cope. The two themes which emerged contribute to our understanding of their experiences and behaviours and suggest possible ways of intervening with children to facilitate the creation of coping goals and responses which will lead to positive outcomes and better adjustment. This chapter will firstly outline the links between the analyses of the current study and the existing literature in the area of paediatric oncology. Proceeding this, the themes - 'Retaining a sense of self-as-normal', and 'Incorporating multiple selves' - will be discussed in terms of their implications for coping. The methodological strengths and weaknesses will then be outlined, followed by suggestions for further research. Finally, the implications of the current analyses for practice will be outlined.

LINKING ANALYSES WITH THE LITERATURE

The research literature reviewed in Chapter Two which was concerned with *coping styles* suggested that an avoidant style was more prevalent during the initial stages of diagnosis and treatment (Smith et al., 1989; Phipps et al., 1995). The accounts of the participants in the current study suggest that this avoidance may be due to a lack of familiarity - both with the people who are now present in their lives, for example the paediatric oncologist, and the hospital environment itself. This is further supported by the children's use of an approach style with those individuals who formed part of their life pre-diagnosis, such as parents siblings and friends. Familiarity may also contribute to our understanding of why participants who spent longer in hospital evidenced greater confidence in engaging with the people and objects common to the hospital environment.

The research literature related to *coping responses*, reviewed in Chapter Two, was focussed on physically observable behaviours and procedures. The emphasis was on the physical body. In the current study, participants spoke about pain, chemotherapy, radiation, surgery, having a hickman versus a portacath, and having tubes and drips. Although participants were often able to describe their physical reactions to various treatments, there were few strategies reported for coping with these, each having varying degrees of success. The strategies utilised were behavioural, such as tensing the body, and sleeping, and were avoidant in style. No evidence was found of cognitive strategies being used. The participants' accounts showed no gender effects, nor did disease chronicity seem to influence the children's experiences.

None of the participants raised the topic of LPs or BMAs, even though these are common procedures that they all would have experienced. This is of note considering the bulk of the literature in Chapter Two focussed on these two procedures. It may be that rather than assessing the prevalence and efficacy of behavioural coping responses for the pain and distress of specific procedures, efforts might be better aimed at capitalising on behaviours and activities normally carried out by children and which could serve to counter the aversive nature of these treatments.

Interestingly, the age/developmental effects mentioned in Chapter Four had little influence on the children's accounts. This may be due to the similarity in age of participants, so that less differentiation of developmental level was evident. *Age at diagnosis* influenced only two aspects of children's accounts - the discussion of contact with school friends and personnel, and the extent of medical knowledge and vocabulary. Five children had already started school prior to diagnosis; of these, three reported more contact with classmates and teachers. One participant, who was the oldest at diagnosis (8 years, 9 months), discussed contact with his school a great deal. This participant also showed greater understanding of medical procedures, reflected in his appropriate use of technical medical vocabulary.

The current study also has links to the research related to psychological adjustment. An interesting link is evident to the study of Bossert and Martinson (1990), who showed children with leukaemia to have more positive perceptions of family functioning than children with solid tumours. While the current study did not examine perceptions of family functioning, the accounts did indicate that children with solid tumours had a more positive perception of hospitalisation than those children with leukaemia. It is possible that the course of treatment for solid tumours, and the more lengthy stays in hospital, may facilitate the incorporation of selves better than the treatment and short hospital stays associated with leukaemia.

Body image was of concern to some of the participants, and while they were willing to discuss their concerns with the researcher, it was clear that these issues were not openly discussed with others. This sensitivity related to body image and functioning may reflect a greater impact of the illness for these participants as suggested by Eiser (1995) in her pilot of the PIE (Perceived Illness Experience) measure.

The qualitative nature of this study results in few areas where comparisons can be made with the empirical literature reviewed in Chapter Two. The following two sections - The Normal Self, and Incorporation of Selves - seek to outline ways in which the current study contributes to understanding the coping of children with cancer while in hospital.

THE NORMAL SELF

The current study, while providing some additional information related to coping with procedures, contributes most to coping knowledge by presenting a possible interpretation of what it is like to be a child living with cancer in the hospital. This information points to possible coping goals, and ways in which children appraise various aspects of the hospital experience. New situations can be frightening, and in the case of children with cancer there are numerous changes in their lives that fall outside what is considered normal for children. The diagnosis of cancer during the childhood years disrupts a time of innocence where the major activity is play, the central elements of which are exploration, experimentation, and learning. It is a very active time and participants were busy finding ways to keep active, or bemoaning the lack of activity. At times this lack of activity was due to poor physical health, but even at those times they *wanted* to play.

The inclination to play is not lost when a child is hospitalised, but it does face some challenges. The main challenge is to the child's sense of trust, a central component within the themes, which influences children's coping with the hospital experience. A major influence on children's efforts to explore, experiment, learn and play is trust. In young children aged birth to eighteen months, a balanced sense of trust is developed through interaction with the world. Babies learn, in their interactions with others, a balance between trust leading to the forming of intimate relationships, and mistrust leading to protection of themselves. If trust dominates, and the child gains a sense of the world as safe, then the virtue of hope develops which entails belief in their ability to fulfil their needs and desires, and confidence in forming relationships with others (Erikson, 1982). Should mistrust dominate, then children see the world as unpredictable, have no belief in their ability to meet their needs, and find difficulty in forming relationships with others.

Trust can be seen as important in forming attachments. An attachment, or relationship, with another person involves active, reciprocal communication, and the bond is strengthened with continued interaction (Papalia and Olds, 1998).

> "...though we tend not to be aware of it, the need to communicate on some level with other human beings - that is, to make ourselves understood or understandable, and in doing so feel cared for, safe, stimulated, and appreciated - remains the prime motivator for all that we do or don't do" (Basch, 1980, p.174).

Understanding the nature of attachments, and their reliance on trust and communication to keep them strong, helps us to see why relationships which children already have with people pre-diagnosis and hospitalisation, are important to maintain. Their existence presupposes the existence of a pattern of trust, and regular communications kept the relationships operating previously.

Maintaining relationships with siblings, peers, and school personnel help the child retain a sense of the world as predictable, and therefore controllable. They trust and rely on the continuation of these attachments. Contact with these people is seen as necessary to maintain the bond, thereby avoiding a sense of loss, and a questioning of the trustworthiness of people in their world. These attachments also give a sense of meaning because, although many things have changed in the children's lives, they need to believe that they, and the people they know, are essentially unchanged. This allows the child's sense of self-as-normal to remain intact.

The relationship between parents and their children is vital in maintaining a sense of self-as-normal because of the primacy of this relationship in a child's life. This relationship, more than any other, is needed to maintain a view of the world as stable; a central component to this relationship between parent and child is trust. Children trust their parents to monitor and control their environment, dealing with any threats which might arise. Implicit in this trust is the perception of parents as all powerful – able to protect them against all manner of ills. Parents are also not expected to be the source of threat to the child. Unfortunately, the paediatric oncology experience, as mentioned earlier, can seriously challenge the trust between parent and child. Unpredictable periods of ill health, reactions to procedures, and reactions of parents under stress, can all contribute to the child's sense of instability, where the trustworthiness of parents is called into question. Cancer and its treatments are a perceived threat that the parent is not only unable to control, but where they are often seen as perpetrators, telling children that they 'have' to comply with treatments.

Children who see their parents as trustworthy are said to be securely attached (Papalia and Olds, 1998). A child who maintains a secure attachment with parents can rely on them to form a secure base from which to confidently explore the environment. This confidence in exploration is important if the child is to become 'at home' in the hospital environment. It places them in contact with new opportunities to retain a sense of self-as-normal through interaction with other children, with toys, games and other child-like activities. Being 'at home' also provides a sense of control through knowledge which is necessary for children to select appropriate coping responses able to influence the situation, for example, ordering food not on the menu.

The relationships with familiar people form the central source of social support for children with cancer in hospital because of the trust that already exists, and the confidence children gain from maintaining links with these people. Highlighting the benefits of maintaining links with familiar people shows also how a lack of maintenance during hospitalisation can affect a child's confidence in meeting new situations, people and challenges. Children, either with limited relationships prior to diagnosis, or who have difficulty maintaining them, may feel as though they are facing the battle alone. This sense of isolation can seriously challenge the children's perceptions of their ability to influence the situation, in turn affecting their coping goals, responses and outcomes.

When maintaining links with familiar people is examined in this way, it forms a pre-requisite for coping with the hospital environment. The maintenance of relationships allows the child to explore and gain familiarity with the hospital environment, giving them a sense of control through stability and predictability. While the part of their life related to cancer and its treatments is largely unpredictable and uncontrollable, the area of their life involving relationships and activities takes on added importance as an opportunity for predictable and controllable interactions to occur. In this way, the coping response - seeking social support - used by participants, serves to maintain secure attachments and trust. The use of the coping responses of seeking social support, engaging in creative and useful activities, and humour, help in retaining a sense of normalcy and controlling the children's interactions with both people, and the environment. The efficacy of these coping responses was reflected in the animation of both voice and body when reporting their use.

INCORPORATION OF SELVES

The multiple selves that emerged from the accounts of the participants were important in coping with hospitalisation. The perceptions of self-as-body-in-pain, self-as-confined, and self-as-patient were important identities to form as they inferred that their cancer and hospitalisation experiences were only part of who they were. These views also served to contain the aversive elements of the hospital experience, preventing them from spilling into, and contaminating the self-as-normal. The children who managed to incorporate the multiple selves were those who were able to balance the self-as-body-in-pain, self-as-confined, and self-as-patient with an intact view of self-as-normal, and emerge with a belief in self-as-survivor-living-with-cancer.

An effect noted in Chapter Four was that of time since completion of treatment, where children who were at a greater distance from completion exhibited a greater willingness to discuss their hospital experiences, reported more interactions with people other than family, and were able to report more positive events while in hospital. Three of the four children who were at a greater distance from treatment had also spent considerably longer as an in-patient (see Table 1 in Chapter Four). It is difficult to ascertain the degree to which each of these two factors - time since completion of treatment and time spent as an in-patient - influenced the coping of participants; time spent in hospital has been focussed on here. Lazarus & Folkman (1984) in their definition of coping include the perception of resources available to master the situation. In the current study participants differed in both their perception and use of resources and this was related to time spent in hospital for three of the four participants. These three participants perceived the availability of a wide range of resources; for example, Bill made use of classmates, friends, the schoolroom, relationships with nurses, humour and mischief in his efforts to cope with hospitalisation.

It could be that time spent in hospital assists in the child's formation of a sense of self-as-body-in-pain, confined, and as patient, as admission to hospital can legitimise the child's requests for support. Admission may also promote greater exploration of the environment, and allow the children's experiences to be visible to others. Children who had extended periods in hospital could be missed by peers and family, visited during hospitalisation, and have their return to normal life celebrated. The longer periods of time spent in hospital may have made it easier for them to habituate to the hospital environment, while shielding them from daily life hassles, for example getting up in the morning to get ready for school. It may also be that more energy was given to retaining a sense of self-as-normal within that environment as the extended time spent there served as a greater challenge to that self. In addition, these children had the presence of a parent one-on-one for the duration of their hospital stay, so social support was more readily available and constant. It appears that children who had shorter treatment protocols, but had spent more time in hospital and were at a greater distance from the end of treatment, seemed to have found a balance in their perceptions so that self-as-normal dominated.

The amount of time spent in hospital was related to the children's coping - those who spent less time in hospital as in-patients reported less interaction with nurses, other children, and the environment. An implication for children treated over longer periods but spending less time in hospital, is that the hospital could remain a foreign, frightening environment, focused even more on aversive procedures, and ill-health. The children who had finished treatment more recently and spent less time in hospital, evidenced less success in retaining a sense of self-as-normal. They viewed themselves as in pain, confined and as patient, reporting fewer coping responses. They were also less willing to discuss their experiences, and reported fewer positive events during hospitalisation.

Children on longer protocols come to the hospital for short periods of treatment, sometimes feeling quite well on arrival, but expecting to feel ill after treatment. The participants on longer protocols, possibly due to less exploration and knowledge of the environment, perceived few resources as being at their disposal, for example Freeze reported that *'everything was boring'*, and his account reported little interaction with either people or the environment. The combination of the short time spent in hospital, the aversive nature of the treatments, and the ill-health that often follows, may serve to create greater difficulties in forming relationships with doctors, nurses, and other children on the ward. Relationships with familiar people are also affected as daily routines are disrupted by frequent but short spells in hospital. The disruption to relationships may serve to compromise the maintenance or building of trust, thereby inhibiting the exploration of the environment and reducing the perceived resources at the child's disposal for coping with hospitalisation.

It may also be that children who spent less time in hospital received less support, both from familiar people and from hospital staff, and had fewer opportunities to gain control and meaning. It is a fine line between keeping things as normal as possible for the child at home, and being unaware of their efforts to gain meaning. Perhaps for them the self-as-normal became the dominant way that *others* perceived *them*, while *they* perceived of themselves as in pain, confined and as patient. It is also possible that those participants at a greater distance from last treatment had gained a better sense of perspective, and that with time the second group would also evidence a dominant sense of self-as-normal.

A central underlying theme for all the multiple selves is that of loss; loss of control over one's body, one's activities, one's ability to make decisions, one's sense of immortality, and loss through death, of one's friends. These losses are major, and if they are permitted to dominate perceptions, then appraisals of the hospital situation will be negative, and the child will feel powerless to influence events. The gamut of losses experienced by children with cancer in hospital represent a world at odds with what was previously believed to exist. This new world must somehow be tamed.

> “‘“What does that mean - ‘tame’?”
> “It is an act too often neglected,” said the fox. “It means to establish ties…One only understands the things that one tames.”’”
> (Saint-Exupéry, 1974, pp.66-67).

The creation of multiple selves was interpreted as an effort to create meaning in the new environment of the hospital, so that the perception of loss did not take over. Children, in fact all people, are continually in the process of looking at their world, the situations and people, and trying to make sense of them. There are those new things which fit into existing perceptions we possess, while others require an adjustment in our categories, or the creation of new categories. When physical illness occurs, the search for meaning becomes an effort to account for the changed circumstances in relation to a “perception of the ability [the individual] has to accomplish future goals, to maintain the viability of interpersonal relationships, and to sustain a sense of personal vitality, competence and power” (Fife, 1994, p.310). The sense of self-as-survivor-living-with-cancer acknowledges the existence of the pain, confinement, and status as patient, but relegates them to the past. This view of self is firmly focused on continuing with life, on looking forward, and taking control once more.

Expectations, both of the children and of others, influenced the children's perceptions of situations, and the coping responses they employed. The coping expectations of others affected the coping responses described by the participants. Realistic expectations, which the child perceived as achievable, resulted in conscious efforts to successfully meet those expectations. Where expectations were perceived as beyond the capabilities of the child, very few strategies were employed and the child utilised phrases such as 'I don't care' in an effort to deny the importance of achieving such goals. This latter scenario affects the self-concept, and further reduces the child's perception of the controllability of their hospital experience.

The child also had expectations of others; those of their family and friends were discussed earlier in this chapter. The remaining core group of people are medical professionals, in particular the doctors and nurses. Doctors were seen in a similar light to parents, in that implicit in their relationship with the children was their 'right' to control over the child's life. This control results from the trust parents give to them to do what is best for their child, and as children trust their parents, it follows that they will also trust their doctors. Interactions between these trusted doctors and participants was limited, but did not appear to be aversive. It is difficult to tell from the accounts whether the children were content with this situation or not. It is possible that interactions with doctors were seen as uncontrollable, and therefore endured, or that the topics of discussion contained within those interactions were serious and aversive, resulting in children being unwilling to engage in a discussion of them. A more probable explanation is that, having deferred to their parents regarding their treatment, the participants relied on their parents to interact with the doctors on their behalf.

The children's expectations of nurses were quite different to those of doctors. Nurses were expected to *'make me feel better'* and respond to the buzzer by asking: *'What do you want?'*, and then *'they get you what you want'*. Implicit in many of the accounts were the expectations that nurses would like the participants, and that this liking would be reciprocated, that the nurse would be known or familiar to them, and that they would play with them. These implicit expectations were influential in determining the children's perceptions of controllability, support and meaning. Being familiar with the nurse gave a sense of predictability, and patterns of interacting and responding could be established imparting control to the child. Support is provided through the trust the participants have that nurses are there to make them feel better, and that they are available when needed. Mutual liking and playing games, interactions which are non-medical in nature, create meaning by assisting the child to retain a sense of self-as-normal. When these aspects were absent in children's interactions with nurses, negative attitudes to hospitalisation were expressed.

STRENGTHS AND WEAKNESSES OF THE STUDY DESIGN

The current study was conducted using a phenomenological design, which has its strengths and its weaknesses. One of its greatest strengths is the focus on participants as experts in their world, and giving voice to those experiences. In describing their experiences to us, children allow us to gain some understanding of how they view the world and construct meaning. Their worldview represents a collection of ideas and representations of the world that organizes events, people and the environment into a coherent, cohesive picture (Ivey et al, 1997). This picture allows them to make sense of the world, and from this picture we are able to form a view of possible ways in which their constructions influence the way they behave. Having access to their perceptions also opens up a new point of intervention, one which may prove more efficacious than those aimed at changing behaviours.

A second strength of this approach is the opportunity it affords us to challenge the assumptions which exist as to the child's perceptions and experiences. This study provided further support for children's ability to provide rich data which can improve our understanding of their perceptions of hospital, and assist in informing practice. Although not part of the formal study design, the researcher spent some time speaking with several parents after the interviews. These parents gave quite different accounts of their children's experiences, remembering quite major crises in their child's treatment, which the participants barely mentioned, or had omitted altogether. Parents' expectations, and memory of their own distress at those times, may create difficulties for children who are working hard on being self-as-survivor-living-with-cancer, and who wish to place the pain, confinement and patient status in the past. It is also possible that those, for whom the self-as-in-pain, confined, and patient was dominant, were struggling to define themselves in reaction to parental efforts to normalise.

Thirdly, phenomenology and the semi-structured interview format utilised in the current study give control to the participants as to what they say, and how much. Giving control to the participants is a frightening endeavour for the interviewer, particularly when the results are needed to create a report or thesis. However, even those participants who chose to test that control by providing few responses, added to the richness of the analysis, and indicated pertinent points in what they *did* chose to comment on, and also what they chose to ignore. An example is of Alvin who would thump his pencil very loudly next to the microphone when he was unwilling to answer a question. Many of the questions he reacted to in this way were related to chemotherapy.

The limitations of the current study mostly relate to the design, rather than the phenomenological methodology. The first weakness is, however, common to qualitative studies and applies to the interpretation of accounts. It is important to keep in mind when reading the analyses contained in Chapters Five and Six, that these are the researcher's interpretations of the transcripts; another person reading those same transcripts may interpret them in a different way. It is also the case that the interpretations do not represent the totality of the hospital experience for children with cancer. It was necessary for the sake of time and space to present only those points deemed to be central to the participants' experiences.

The remaining limitations refer to design features. Firstly, all the children interviewed were previously known to me which, although an advantage in terms of rapport, may have influenced the children's accounts so as not to negatively impact future encounters with me. It may also have resulted in bias during the analysis stage, even with constant vigilance and questioning of interpretation with the original transcripts. A second weakness lies in the newness of the formal interview situation. The difficult ethical process resulted in over-sensitivity to questioning the child beyond what they spontaneously offered, evident in a reluctance on several occasions to draw out explanations and clarifications.

Parental influence was a limiting factor for two reasons. It is difficult to gauge the impact of the presence of parents in three of the interviews. Their presence was felt by the researcher, which may have resulted in restraint during interviewing in order not to offend parents, rather than for fear of upsetting the child. The second area of parental influence was concerned with the lack of control for the information parents shared with children prior to the interview. Discussion with some parents after the interview indicated that they had been discussing the hospital with their child in the days leading up to the interview, whether this led to greater openness during the interview, or contamination of the child's account, is difficult to gauge.

The last three points are not limitations, but more of a comment. Firstly, the putting aside of meaning mantle was not easy in that, once set aside, the mantle remained off until the completion of the study. At several points during the analysis and writing, it was necessary to question my information as previous assumptions crept in and biased the interpretation of the transcripts. Secondly, it is pertinent at this point to remind the reader that the aim of phenomenology is not to provide information for generalisation across all children with cancer. The interpretations presented in this thesis refer only to the experiences of the participants. While this information may be useful in understanding the hospital experiences of other children with cancer, this study does not claim to have provided a definitive description of children's experiences.

Thirdly, although the fact that none of the participants were currently hospitalised at the time of interviewing was initially seen as a limitation, it may be that the memories remaining up to two years after hospitalisation are even more pertinent as they illustrate those experiences which do not fade into insignificance. That is, they may represent some core aspects of the hospital experience for these children.

FUTURE RESEARCH DIRECTIONS

The length of protocol, and time since end of treatment, are worthy of further investigation as they appeared influential in forming children's perceptions of their hospital experiences. A follow-up of participants who had completed treatment more recently could possibly indicate whether perceptions of self-as-normal become more dominant with greater distance from treatment.

The disparity in time spent in hospital also raises a topic for future qualitative research. What are the hospital, school and home experiences of children with cancer? Do the differences between children's hospital experiences, evident in the current study, also appear in their experiences outside this environment? A longitudinal study involving interviews of the children, family, teachers and peers, could provide support for the presence of multiple selves, and whether they appear at particular points in the diagnosis/treatment/recovery process. Research in this area may point to possible areas where incorporation of multiple selves may be problematic, and benefit from intervention.

A related area for future research is an exploration of the expectations of the people involved in the paediatric oncology experience. What do doctors, nurses, parents, siblings, teachers, peers, and the child expect - of each other, themselves and the situation? Research in this area could highlight the disparate coping goals of the various people, and indicate areas for intervention. The study of expectations would benefit from the inclusion of quantitative data, such as diagnosis, number of school days missed, and family functioning. This data would assist in exploring the degree of fit between the perceptions held regarding the hospital, school and home experiences, and what is physically recorded; possible common misperceptions may emerge.

IMPLICATIONS FOR PRACTICE

The implications of this study for the field of paediatric oncology revolve around two concepts - the first is communication, the second is expectations. All those who are concerned with the well-being of the child with cancer in hospital are influenced by these two concepts. As outlined earlier, communication is necessary to form and maintain relationships with people. Greater consideration of the ways in which the child communicates, and is communicated with, will assist the child to feel valued and heard.

The concept of communication is of particular importance for retaining a sense of self-as-normal. It relies on the awareness by parents and teachers of the child's need to interact with others. Parents are vital for both maintaining links with familiar people, and for becoming at home in the hospital. Through communication with the remainder of the family, the school and friends of the child, the parent is able to influence the degree of contact maintained. This is particularly important for children who are hospitalised for long periods. Parents also communicate either trust or mistrust of the environment via their interactions with their children. The protective instincts of the parent are understandable, but the child can still be encouraged to explore with the parent present. As both parent and child gain confidence with the environment, they gain greater confidence and the child can achieve some degree of independence.

Teachers have a role to play in maintaining links to familiar people. Although visits to the child in hospital are appreciated, they are not necessary. However, communicating with classmates of the child with cancer (with the family's permission), is helpful for maintaining contact, and may assist with school entry. Communication with the child based on trust and mutual liking can result in comfort and reassurance for the child, greater interaction between child and communicator, and an increased feeling in the child of safety and confidence.

An important area of communication is that of expectations. The people involved in the care of children with cancer in hospital, and the children themselves, could benefit from making explicit the expectations they hold both of others and of the situation (Genevro et al., 1996). These expectations affect the behaviours of all parties involved, and can also colour perceptions of others' behaviour. Only through making expectations explicit can misperceptions be noted and rectified. For example in the current study, children expected nurses to come quickly when they pressed the buzzer. If the nurse does not respond immediately, the child may perceive that the nurse doesn't like them, that they shouldn't ring the buzzer, or that they are alone. Any of these perceptions may result in the child being less confident in utilising the buzzer at another time. Nurses, on the other hand, may expect the child to know that they will come, but that they are busy and the child may need to be patient on occasion.

The children's perceptions of self-as-body-in-pain, self-as-confined, and self-as-patient, contain implicit expectations. For example, the self-as-body-in-pain may have the expectations: When I have a prick, it will hurt. By asking children to express their expectations, a dialogue is started from which coping goals and response options can be formed. The child may be asked to articulate ways of either reducing the pain, or coping with its existence. Discussion of children's expectations may best be conducted with psycho-social support staff in the first instance. As the child formulates plans for utilising coping responses in various situations, parents and medical professionals should be informed, so that they can make efforts to elicit those responses.

Communication, and especially of expectations, is not an easy task within the hospital environment of busy medical professionals, concerned parents and sick children. Education and psycho-social support of children and families are needed on a regular and ongoing basis to facilitate these activities. This has particular relevance for those children whose protocols are longer, and who spend less time in the ward. Children who are infrequently in hospital have limited contact with psycho-social support staff, and any difficulties they may be experiencing could go undetected until they reach crisis point.

CONCLUDING COMMENT

Hospitals are seen as places of illness serious enough that outside help is needed. They are often seen as places where people die, and are in a lot of pain. Cancer is also seen as a serious illness, where outside intervention is imperative, and where the outcome is sometimes death. In the hospital experiences of children with cancer, the words hospital and cancer overpower what is the most essential object - the child. The accounts of the children in this study provided a clear reminder that they are first and foremost children and, while the treatment of the cancer may be of primary concern for their parents and the medical staff, they mainly want to play and be like normal children.

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Common Side-Effects of Cancer Treatments

Body System	Common Side-Effects of Chemotheraphy	Side-Effects of Radiation Therapy Early Reactions (occurring within days or weeks)
Digestive tract	Nausea, vomiting, diarrhoea, constipation, heartburn	Nausea, vomiting, diarrhoea, loss of appetite, bowel urgency
Eyes		Redness
Mouth	Change in taste, mouth sores	Soreness, dry mouth
Skin/hair	Hair loss, inflammation, dry, itching skin, moist skin, rashes, sun sensitivity	Redness, blistering, hair loss (after about 2 to 3 weeks), puffy ears
Lungs		Dry cough
Urinary tract		Bladder urgency
Bladder	Bladder irritation and infection, bloody or discolored urine	
Nervous system	Numbness, difficulty walking, hand tremors, jaw pain, drooping eyelids, weakened hand grasp, seizures	
Systemic (involving the entire body)	Fever, bone marrow depression (child has low WBCs, RBCs, platelets), allergic reaction – fever, fainting, rash, difficulty breathing, loss of appetite, increased appetite, weight gain	Fatigue, bone marrow failure (depletion of white and red blood cells, resulting in bleeding and loss of immunity
Other	Lung irritation – cough, shortness of breath, difficulty breathing, hearing loss	

Appendix B

NOTICE FOR CCF NEWSLETTER

Children with Cancer - Their Hospital Experiences

Hi, my name is Véronique Rochecouste, and I am a Masters student at Massey University. I am doing a research project on the hospital experiences of child cancer patients. I am hoping to interview up to ten children, aged between 5 and 10 years, while they are at Wellington Hospital as in-patients. I will be interviewing from September to the middle of November. If your child fits this description and you would like information about the study, or wish your child to participate, please contact me. Contacting me is simply a request for information and does not mean you **must** take part in the study. I can be contacted in the following ways:

Snail mail: [redacted] -

Phone: [redacted]

E-mail: [redacted]

Massey University
COLLEGE OF HUMANITIES & SOCIAL SCIENCES

School of Psychology
Private Bag 11 222,
Palmerston North,
New Zealand
Telephone: 64 6 356 9099
Facsimile: 64 6 350 5673

INFORMATION SHEET

"Children with Cancer - The Stories of their Hospital Experiences"

Researcher: Véronique Rochecouste
Position: Masters Student
Address: [redacted]
Phone: [redacted]
E-mail: [redacted]

Supervisor: Dr. John Spicer
Position: Associate Professor
Address: School of Psychology
Massey University
Phone: (06) 350-5799 ext 2070
E-mail: J.Spicer@massey.ac.nz

You and your child are invited to take part in a study about your child's hospital experiences. You will have plenty of time to consider if you and your child would like to take part. Reading this information sheet does not mean that you **must** take part. **Your participation is entirely voluntary (your choice). You do not have to take part in this study, and if you choose not to take part your child will receive the usual treatment/care".**

If you do agree to take part you are free to withdraw from the study at **any time**, without having to give a reason and this will in no way affect the continuing health care of your child.

What is the Aim of the Study?

- To give children the opportunity to tell their story.
- To present these stories in a form easily read by a wide range of people involved in their care.

Who are the Participants?

- The participants are people who have responded to the information posters, and agreed to take part.
- There will be from 5-10 participants.
- The participants will be children with cancer, aged 5 - 10 years.
- All participants will be in-patients at Wellington Hospital.

Where will the study be held?

- The study will be held at Wellington Hospital, on either Ward 18 or 19.

How long will the study take?

- The study will take eight months, but participants will only be required for approximately two hours.

What will happen during the study?

- Once you and your child have agreed to participate, I will have an informal chat with you all. At this time, I will ask a short series of questions regarding: who the members of your family are, where you live, your child's age, type of cancer, age at diagnosis, and approximate number of previous stays in hospital. This chat will take approximately 30 minutes.
- Next, I will interview your child. I will audio-tape the interview. During this interview you, the parents/guardian, will not be present. This is important so that your child can tell their story without distraction. I'll start the interview by asking: "What is it like to be a child with cancer in hospital?" For the rest of the interview I will take my cue from your child. No direct, or leading questions will be used. ***Your child may stop the interview at any time.***
- Only one recorded interview with each child is planned, up to a maximum of one hour. However, due to the health needs or attention span of your child, it may be necessary to hold up to three shorter interviews, still with a maximum overall time of one hour.
- Finally, I will do a follow-up visit with you and your child approximately one week after the interview. At this time, I will ask if you have any questions about the interview, or study. This visit will also take approximately 30 minutes. After one month I will contact you to answer any questions, or receive any comments regarding the interview process, and its effects on your child.

What happens to the information that my child provides?

- The only people who will have access to the tapes and written copies of the interview are: your child, myself, and my supervisor (Dr. John Spicer). This information will be safely stored at Massey University.
- No material which could personally identify you, or your child, will be used in any reports on this study.
- Your child will select a nickname for the purpose of the interview, so that their real name will only be known to me.

What are the risks?

- This is a non-therapeutic study, and no risks are anticipated. Should the interview raise any emotional or psychological issues for you or your child, you may contact:

1) the pediatric oncology social worker: Lynette [redacted],
   phone: [redacted]
   or
2) the child psychologist: Ulla [redacted]
   phone: [redacted]

- There is no financial cost to you and your child taking part.

What are the benefits?

There are three main benefits:

- A chance for your child to tell their story: to express fears, worries, anger, confusion, joy, peace, or funny happenings about their hospital stay.
- You, as parents/guardians, will also benefit by receiving feedback from the interview in the informal follow-up session, and through the final written report, which will be sent to you when the study is finished.
- Finally, the professionals involved in the care of your child will also receive a report on the results of the study. This report may be useful in helping them to understand how children with cancer in hospital might feel.

What will happen at the end of the study?

The following reports will be sent at the finish of the study (this may not be until mid-May, 2000):

- A report will be sent to you and your family, to the central branch of the Child Cancer Foundation, and to the National Office of the Child Cancer Foundation.
- A report will be forwarded to the pediatric oncology team at Wellington Hospital.
- An article based on this research will be submitted to academic journals for publication.

Where can you get more information about this study?

- You may contact me, or my supervisor, at any time with questions about the study.
- If you have any concerns about the study, you may contact:

The Wellington Ethics Committee
Wellington Hospital
Phone: [redacted]

Who has approved this study?

- This study has received ethical approval from:
  - the C.R.H.A. Wellington Ethics Committee, Wellington Hospital
  - the Massey University Human Ethics Committee

Please feel free to contact the researcher if you have any questions about the study.

Appendix D

Massey University
COLLEGE OF HUMANITIES & SOCIAL SCIENCES

School of Psychology
Private Bag 11 222,
Palmerston North,
New Zealand
Telephone: 64 6 356 9099
Facsimile: 64 6 350 5673

CONSENT FORM

"Children with Cancer - The Stories of their Hospital Experiences"

I have read and I understand the information sheet dated ________________ for volunteers taking part in the study designed to understand the hospital experiences of children with cancer. I have had the opportunity to discuss this study . I am satisfied with the answers I have been given. YES/NO

I understand that taking part in this study is voluntary (my choice) and that I, or my child, may withdraw from the study at any time and this will in no way affect my child's continuing health care. YES/NO

I understand that our participation in this study is confidential and that no material which could identify me, or my child, will be used in any reports on this study. YES/NO

I have had time to consider whether my child should take part. YES/NO

I know whom to contact if I, or my child, have any emotional or psychological issues as a result of the study. YES/NO

I know whom to contact if I have any questions about the study. YES/NO

I consent to my child's interview being audio-taped. YES/NO

I wish to receive a copy of the results. YES/NO

I ____ hereby consent to my child ____________________________________taking part in this study.

If you have any concerns about the study, you may contact:
The Wellington Ethics Committee,
Wellington Hospital, telephone 385-5999 ext 5185

Date: **Signature:** **Signature:**

Signature of witness:

Name of witness:

Full name of Researcher: Ms. Véronique Rochecouste

Contact phone number for researcher: [redacted]

Project explained by: Ms. Véronique Rochecouste (Researcher)

Date: **Signature:**

Massey University
COLLEGE OF HUMANITIES & SOCIAL SCIENCES

School of Psychology
Private Bag 11 222,
Palmerston North,
New Zealand
Telephone: 64 6 356 9099
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INFORMATION AND ASSENT FORM

CHILDREN WITH CANCER IN HOSPITAL

Hi, my name is Véronique. I want to talk to children with cancer about what it is like to be in hospital. I will tape my talks with children, and write a book for my teachers at school, and the doctors, nurses and families here at the hospital. The book will have the things that children think about hospital, but nobody will know exactly what any child said, because everyone I talk to will choose a special nickname.

I would like to talk to you about how it feels to be in hospital. It will mean talking on your own with me, with a tape recorder in the room. The longest we will talk for is an hour. If you, and your parents, agree to talk to me, and you feel tired or sick, you can ask me to stop. If I think that you are not feeling well, I will ask if you want to have a break, or stop. We can talk again another day. If you don't like what we are talking about, you can ask me to stop, or I might ask if you want to stop. I will do my best to make our talk fun, and not ask you anything you find hard to answer.

If you talk to me and then decide you don't want other people to know what we talked about, you can tell me, or your parents, and I will erase your tape. If you have any questions about what I am doing, you can ask and I will try my best to answer your questions.

After the book has been written, you can choose what happens to your tape. You might want to keep it, you might let me use it to help other children understand what it is like to be in hospital, or you might want me to erase it.

I, ____, have read, or been read, this information sheet. I agree to be interviewed.

Date:

Signature/Mark:

Signature of Witness:

Name of Witness:

DEMOGRAPHICS QUESTIONNAIRE

Father's name:

Mother's name:

Guardian's name:

Child's name:

Child's age:

Child's diagnosis:

Child's age at diagnosis:

Approximate number of overnight stays in hospital:

Date of last treatment:

Siblings' names/ages:

Address:

Phone:

INTERVIEW GUIDELINES

Initial question:

What is it like to be a child with cancer in hospital?

Possible prompting questions:

What is it like to be in hospital at night?

What is it like to have…[that] treatment?

What is it like to talk to the doctors?

What is it like when your sibling/s come to visit?

What is it like to go to school in the hospital?

What is it like to eat all your meals here?

What is it like to be in isolation?

What is it like to be hooked up to an I.V.?

What is it like having a portacath?

What is it like when you feel…[angry, sad, happy, annoyed] like that?

What is it like when you're feeling tired?