NEGOTIATING INFERTILITY TREATMENT DECISIONS

A THESIS PRESENTED IN PARTIAL FULFILMENT
OF THE REQUIREMENTS FOR THE DEGREE OF
MASTER OF SOCIAL WORK
MASSEY UNIVERSITY
PALMERSTON NORTH, NEW ZEALAND

ANNA THORPE

2004

Errata

Page	Line	Correction
ii	19	'for' instead of 'fro'
1	12	'fertilisation' instead of 'fertililisation'
14	18	delete 'a'
17	11	add 'an' before 'unexpected'
18	8	add ':' after '2001b'
43	13	'compromised' instead of 'comprised'
70	3	apostrophe after 's' in participants not before
84	11	'and' not 'is'
137	16	add apostrophe after 'counsellors'
140	13	delete 'on'
143	3	add apostrophe after 'participants'

ACKNOWLEDGEMENTS

This thesis would not have been possible without the time, support, insight and reflection of many people. Firstly, to those fifty two people who told the intimate stories of their journeys negotiating the infertility treatment treadmill - the telling of which involved risk, trust, tears, laughter as they thought and spoke about an area many would feel more comfortable putting behind them. Thank you from the heart.

Professionally, to The Fertility Centre (formerly the IVF Unit of Healthlink South), who employed me as a counsellor, helping to consolidate this path, and provided access to respondents in the main study, along with the Donor Insemination Unit of Otago University. To Peter Benny, Iris Sin and Cynthia Spittal and to the Christchurch Medical Librarians. To the New Zealand Fertility Society (now fertilityNZ) for their 1992-3 Summer Studentship, and to John Peek. To the Christchurch Fertility Society for promoting the preliminary study.

To Celia Briar, my chief supervisor, for her unending patience, her light guiding touch and her clear analysis. To my other supervisors, Mary Nash, Mervyl McPherson and Ruth Anderson for their helpful feedback. To the Massey University administration fro their flexibility and to the Massey Distance Librarians. To the Ethics Committees of Massey University and the Southern Regional Health Authority for their approval and useful input.

To my dear partner John whose love, encouragement and academic understanding were practical, motivating and firm. For his warm hand through the hard times of losing our son after years of infertility, in the midst of this study. To our miracle boys, Fergus and Alec, for arriving in such an intense rush, teaching me that life is to be lived fully in the present. And to my family, friends and colleagues for standing alongside supportively.

Thank you all.

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ABSTRACT

The focus of this thesis is on how couples make infertility treatment decisions, from infertility diagnosis through the maze of available options, until they decide to stop treatment and move on, either with or without children. The decisions required along the infertility treatment path are dazzling in their breadth, detailed in their technicality, physically daunting, emotionally demanding and ethically stretching.

The research was qualitative and involved two studies. The preliminary study involved six couples who were understood to have 'moved on' from infertility treatment, although it emerged that most had not clearly stopped. The main study involved twenty couples who had undergone a minimum number of either donor insemination (DI) or *in vitro* fertililisation (IVF) cycles in Christchurch, New Zealand. The research was longitudinal, with three interviews held over two and a half years. This enabled the development of an original model of treatment status, in which participants were categorised as 'active', 'non-active', 'in limbo' or 'stopped' with their treatment. The model aids in understanding the positioning and movement of people's infertility status over time. Limbo was relatively common, despite being under-recognised in the literature.

The major factors influencing how couples make infertility treatment decisions were examined. Childless women were found to drive couple's treatment decisions, while parents were more likely to make joint decisions. Emotional strain, age, and cost were factors that affected the decision to have more treatment, and got extended over time. The "lure of a cure" (May, 1995:236) through an advancing and increasing range of assisted reproduction techniques tended to delay the decision to move on from infertility treatment, as did 'anticipated decision regret' (Tymstra, 1989). Counselling, though valued, was not found to have assisted many participants in their decision-making. The decision to stop treatment was therefore often prolonged and difficult, especially for those who were still childless.

INTRODUCTION

Infertility Treatment Decisions

> "You step on a treadmill... and you had to do everything in order for you to feel that you had done everything. Then there is always 'oh don't worry, we'll get you pregnant', sort-of a carrot being dangled. We wanted someone to say that too - it was our dream as well. I don't think I actually believed I was infertile. I thought he would say 'look it's just something minor and you will be right. I will give you a drug, a wonder drug and you will be fine'." *Clare*

This thesis is about how people make infertility treatment decisions - from the start when infertility is first diagnosed, through the maze of possible treatments, until they have completed their family through various means, or a decision is reached to stop treatment and move on to a different phase in life. The experience of infertility is often likened to a journey - toward a child, toward resignation, toward self-knowledge (Michie & Cahn, 1997:98). This journey through the world of infertility is difficult and uncertain. It starts in the privacy of one's home and, over time, moves toward the doctor's office (Glazer & Cooper, 1988:xx), where the personal experience of infertility is put under the microscope and a diagnosis of the problem (hopefully) made. There, a range of medical treatments is offered, involving varying degrees of intervention, cost, time, stress, third party involvements and success. Multiple decisions will need to be negotiated and navigated (Greil, 1991:78), which will have enduring consequences (Diamond, Kezur, Meyers, Scharf, & Weinshel, 1999:220). How people come negotiate these infertility decisions is the focus of this thesis.

> "It's the same secret as making really good decisions about anything - knowledge, experience, understanding. Well, we didn't have any of that." *Dillon*

The power of the spoken word

In valuing the power of narratives to explain and interpret life, I wanted to let the participants speak for themselves as much as possible (Sandelowski, 1991; Stiles, 1990). Therefore, direct quotations are used wherever possible, to illustrate points in the text. The people who took part in the study were very open and articulate about what the infertility experience meant and many of these narratives are best left as intact as possible to preserve their essential meaning and the power of their message. All quotations from the study have quotation marks and the chosen name of the respondent, for anonymity, in italics. The participants of this study are the *story-tellers* about their lives with infertility, the choices they made and how they negotiated the treatment treadmill. This man explains...

> "You're in a tunnel that you can't see any light at the end of it and you're fixed into a schedule, a monthly schedule, and you have your ups and downs and you're going through it and you're never really sure when it's going to end... You can't get away from it... You're either working up to it and anticipating, or you're on the down side thinking 'damn, we'll need to wait another month and spend more money and the people are incompetent... You're searching for something, you're searching for a solution." *Frank*

The story of the study

When I first embarked on this study I was particularly interested in the dilemma of stopping infertility treatment *without* having a child. Without the child they hoped for, dreamed of, tried so hard for - how did people get to this point? Could they get to that point of acceptance and decisiveness? How could people exert some sort of strength and resolution, yet honour their emotional response to infertility? Who helps people through the challenging process of moving on from treatment empty-handed? Could people, who have really wanted and tried to have children, feel fulfilled and satisfied without them? Decision-making processes in this area appear to be taken for granted. The medical system provides a work-up of tests and progression of treatments to follow, but no model for ending treatment with dignity.

It was wondering about these questions that I recruited participants for the preliminary study of a PhD in 1993. Eventually six couples were found by word of mouth who were understood to have stopped infertility treatment and moved on. A qualitative interview consisting of mainly open-ended questions took place with each couple, producing a mountain of recorded material. During the interviews it emerged that two thirds of the participants had *not* in fact moved on from treatment - they were either having a long break ('non-active') and intended to return to treatment, or they were unsure ('in limbo') about whether to resume treatment or stop altogether, as was this woman.

> "I've got this lovely frieze, the ABC's of animals to put around a child's room. I started buying (baby) things donkey years ago. Sometimes not specifically just for me, but certainly not intentionally for someone else. A nice wee gown or a wee outfit or cute coloured bright suits... We bought one toy together, it's waiting in the wings, just to be ready for when we have children... It was always 'when', I guess now the doubt has crept in... We couldn't go on in limbo forever." *Charlotte*

This was enormously revealing on many levels. It demonstrated how prolonged, difficult and ambivalent stopping treatment could be. It also highlighted that people do not just move from being in active infertility treatment to stopping. In between these two treatment statuses of active and stopped can be an extended period of time and movement. During this phase, people can change what they do depending on opportunity and the personal space they are in. They can be non-active – wait and take a break. They can also be in limbo - unsure or not agreed in the relationship how to proceed with their infertility treatment. With this increased understanding and because of the challenge of recruiting more couples who were supposed to have stopped infertility treatment, I chose to expand the original research.

The sample of the main study was changed to target people who had at least three donor insemination (DI) cycles or at least two *in vitro* fertilisation (IVF) cycles through Christchurch fertility clinics. The intention of targeting respondents who had undergone a moderate to higher number of treatment cycles, was to learn from their longer experience of infertility treatment. The main study was designed to be longitudinal, to take several snapshots of participants' lives and decisions, in order to track their decisions, treatment statuses and family situations. From 1994 until 1997, three interviews took place with twenty couples – ten from DI and ten from

IVF. A great picture unfolded of these forty peoples' lives and infertility over that time.

> "Being fertile, or being able to have children naturally hasn't been the norm... You see the instances of infertility popping up all around you. It's like when you buy a white car, you notice all the other white cars. It's looking for the norms, in those 'un-norms' around you and it's just amazing the instances of it." *Nicholas*

Participant couples had experienced infertility for an average of seven years. DI couples had tried an average number of 15 DI cycles, ranging from three up to thirty cycles. Three of those DI couples then tried up to nine IVF cycles (usually with donor sperm, but also with the man's sperm using ICSI). In comparison, IVF couples had undergone between two and 11 cycles, with an average of five IVF cycles. Almost half the participants had undergone surgery for infertility. They had spent an average of $9,000 for DI couples and $11,000 for IVF on infertility tests and treatment. Two thirds of couples ended up with children through treatment, adoption or naturally. One third had none. Two families were blended - naturally conceived children together with siblings from DI or adoption. Two women had adopted out children when they were younger. Two men were infertile after treatment for cancer. Three people had children to former partners. Two men had undergone vasectomies and needed DI after unsuccessful reversals. Half the couples had experienced loss of pregnancy, up to four times. One couple separated during the study. These are the stories of people's lives.

> "I come from a background where my family were violent, where I was an incomplete child. I could never be tall enough, fast enough or strong enough or smart enough as a child growing up in my home environment... I could never give my parents the child they wanted, but I could possibly give my own child the father that he wanted. So it's bloody hard for me, because I am entering an adult relationship, an adult environment, where I can never be the complete father, the ideal father, the good father." *Samuel*

The main study developed a wider range of questions about infertility treatment decision-making from the beginning of treatment until people stop and move on. These questions under study are complex, and informed by both the personal meaning and social context of infertility, forming interconnected strands to enable us to see the whole picture (Hera, 1995) of how infertility treatment decisions are made. I was interested in whether conscious decisions were made to start and stop treatment, and who in the relationship took on the decision-making responsibility with infertility treatment. I wondered about what limits people had in terms of their treatment, and whether these limits got pushed back over time, if they were unsuccessful. I was curious about what stopped people having treatment in the end and the processes they used to stop. I assumed that it was much easier for parents to move on from treatment. I wondered about differences between parents and childless respondents, between men and women, and between those having DI and IVF. As an infertility counsellor, I wanted to know what input counsellors should be providing into infertility decision-making. As an infertile woman, I was interested in whether it would be helpful for a counsellor to disclose a personal experience with infertility.

The issues and literature that inform the topic of infertility decision-making are vast, straddling the inter-connected fields of social work, sociology, psychology, nursing, statistics, medicine, anthropology and religious studies. Placing boundaries on what was, and what was not central, was challenging. The thesis is not about specific infertility treatments, like third party reproduction. It does not focus on the stress caused by infertility and the coping response to it. Nor does it target people who decided not to start infertility treatment - those who may call themselves 'childfree' (see Appendix 19). The thesis concentrates on those who step onto the infertility treadmill and how they make decisions among the plethora of treatment alternatives available, until they step off - either with children or without.

Locating myself

Why was this topic of infertility decision-making important to me? In 1993, when this research was started as a PhD in Social Work, I had been living with, and thinking about, infertility for several years. Over ten years of infertility, I underwent various diagnostic tests and surgeries and had an ectopic pregnancy and traumatically lost a son, who was stillborn. I had a deep yearning for children. Infertility brought significant challenges to my sense of self and many losses and issues to contend with. However, at the same time, I felt ambivalent about having treatment for infertility and felt I could lead a satisfying life without children. My partner and I did decide to go ahead with infertility treatment and had two IVF unsuccessful cycles. We experienced being caught up in the multitude of decision-making required to determine what, when and for how long to undergo treatment.

Just prior to a third IVF cycle, I spontaneously conceived. Our son was born extremely prematurely at 23 weeks, lay critically in the balance for months. Before his due date for delivery and while he was still in hospital, I rather miraculously became pregnant again. This son defied the odds and stayed put until 33 weeks, with hospitalisation and bed rest. At the end of ten intensely stressful months, we were blessed with two very small sons. The PhD study, initially put on hold with one fragile son, was brought to a standstill with two. The almost completed research sat quietly for almost five years, before being restarted as a Master of Social Work - to honour the stories told by the participants and to bring closure and completion. Thus the study focus and process for me as researcher was an intensely personal one, congruous and challenging, as well as interrupted and concluded.

As a social worker, my background was in community development, including a wide spectrum of women's health and reproduction issues, working along the continuum to promote choice and access to services. At the same time the research project was initiated, I began work as an infertility counsellor at the IVF clinic in Christchurch, later to become The Fertility Centre. In this professional counselling role (see Chapter Five), I met with all people undergoing IVF, some of whom had been on the infertility treatment path for up to 15 years. The vast majority of them had never met a counsellor before, did not know what to expect or how to use that time together. Thus, I became interested in the most helpful counselling roles for people facing infertility, to help empower people to make infertility decisions in their lives, which were of great and enduring personal significance.

These strands of personal, professional and researcher are clearly intertwined, integrating knowledge and understanding into who I am - as a woman, a social worker and a student. Consequently, this study is the result of a complex interplay of roles, knowledge's and skills (Sieber, 1982:181). Without this combined awareness, energy and commitment, this project to explore decision-making along the infertility journey would never have been begun.

The structure of the thesis

In understanding why people make the infertility treatment decisions they do, it is important to understand what infertility is and what it means for people. Chapter One contains definitions and descriptions of infertility. It describes the two main infertility treatments that the sample drew on - donor insemination (DI) and *in vitro* fertilisation (IVF), as well as adoption which was chosen by several participants. The chapter then introduces the extensive infertility literature on psychosocial issues. Why do people want children and what is meant by infertility as an unanticipated life crisis? What difference does gender make in the response to infertility? The context of decision-making in infertility treatment is discussed, along with why people persist with treatment and the motivating concept of 'anticipated decision regret'. This background detail is important, as generally participants felt that society is ignorant of the impact of infertility (Sandelowski, 1993), noted by this woman, who said that for

> "A lot of people, it's abhorrent to think of the things you do if you're infertile - interfering with nature and things like that... I find people who make those kind of comments, they're sitting secure at home with their two or three children and it's never been an issue for them. It's very different if you're in that situation." *Sarah*

In seeking to understand how people make infertility treatment decisions, *how* the data was collected and analysed was essential for developing valid results. The qualitative methodology of the study is discussed in Chapter

Two, starting with the overlap of the personal with the research topic. Recruiting participants who firstly had moved on from treatment for the preliminary study, and secondly, those who had undergone a minimum number of recent DI or IVF cycles for the main study is considered, as well as the choice of interviewing couples. A vast mountain of data was collected from the closed and open questions, which required rigorous methods of organising and analysing the data honourably, guided by clear ethical principles. Following two detailed tables summarising the characteristics of the respondents in the main study, the infertility paths of these forty people are covered in depth. Some questions in the interviews were found probing.

> "It's not something you can think about for five minutes and then have the answers like that. I mean it really is a soul searching question." *Ian*

From the three snapshots of interviewing in the longitudinal study, an original model of infertility treatment status was develop - to understand the positioning and movement of people's infertility treatment decisions over time. This is model is introduced and applied to the participants in Chapter Three. The four treatment statuses are 'active' for those having infertility treatment; 'non-active' for those having a break between treatment cycles, while intending to resume; 'in limbo' for those who cannot decide whether to resume treatment, or stop and move on; and 'stopped' for those who have clearly quit infertility and moved on to a new stage of life, either with children from various means, or without children. Participants were found to take multiple steps; to enter, exit, re-enter phases at any point (Bitzer, 2002:14), usually moving from being active, through to being non-active or in limbo, towards 'stopping' treatment. The very nature, direction and length of the fertility treatment path was fluid, and highly individual (Gordon & Barrow, 2000:504), and involved changing treatment paths and the timing of treatment along the way. Being in limbo has not been sufficiently recognised in the literature, despite being relatively common, as this woman says.

> "The other thing was feeling in limbo... because I didn't have any control over really where my life was going."
> *Sarah*

From that vast mountain of data, results on treatment decision-making were formulated. Chapter Four covers key participant decisions on starting treatment after diagnosis; continuing treatment through the maze of different options; to stopping treatment, either when people have enough children or have had enough treatment. The influences of gender and parental status on decisions are discussed, along with spiritual values. The main limits to having further treatment are identified, and those that got extended with time. How participants made their treatment decisions, and how this fits with decision-making literature, is reviewed. What respondents experienced, or anticipated feeling, after moving on from treatment is discussed. Moving on is particularly challenging for those without the children they yearn for, expressed by this woman.

> "Sometimes I do feel a lack of purpose... Ultimately I would still love to have a child. Until I get over that, I don't think I will ever move on." *Maureen*

Professionally, I was interested in the role of counselling with infertility treatment decision-making. Chapter Five focuses on the implications role of infertility counsellors - helping people to make considered informed decisions with which they can live (Glazer & Cooper, 1988:37). Results cover what participants *would* have found helpful for their decision-making and this is compared with the decision-making counselling they actually received. Accessing counselling to assist with decision-making is discussed, as is the strong call for follow-up counsellor contact after treatment failure. Results showed that most would find it helpful to have counsellors disclose a personal experience with infertility, as this man said.

> "Because you're in the same boat as people you're questioning, I feel you have more feelings towards the people you are interviewing... Someone who has been trained up... they can ask all the right questions and they can nod their head at the right time and do all the things visibly and outwardly, but they can't *feel* it. They can't <u>know</u>... I've got the feelings, Jane's got the feelings, you've got the feelings... People who haven't can't understand that." *Bill*

Chapter Six concludes the thesis and is divided into three sections. Firstly, the context of choice in assisted reproduction is re-examined and results of the thesis reviewed, along with their implications for people experiencing infertility. Secondly, questions are raised as a result of the research, and directions for professional practice offered to those providing infertility services, including counsellors. Finally, the research process is reviewed, with direction offered for further study of infertility decision-making.

> "I hope you write a book out of it, or even a paper or something, that everybody can use that's here... I just figure that if it's done here and it's by us, for us and that everyone will have a better understanding of it, because we've got our own lifestyle... I just hope you do it." *Joe*

CHAPTER 1

Infertility Treatment Decisions: Context and Perspectives

In order to understand how infertility treatment decisions are made, it is necessary to understand what infertility is and what it means to people. This chapter firstly provides definitions and descriptions about infertility and treatment. The second part of the chapter discusses the issues and themes in the current literature that inform professional and academic perspectives on infertility treatment decision-making.

> "You feel that there's no way... without having children.
> You can't visualise a future without them." *John*

What is infertility?

The definition of infertility can vary. Infertility is generally defined as being unable to conceive a viable pregnancy following one year of regular, unprotected sexual intercourse (Coney & Else, 1999:11) between a man and a woman, or an inability to carry a pregnancy to live birth (fertilityNZ, 2003a). While in Australia, a couple is regarded as infertile when they have not conceived after twelve months of unprotected sexual intercourse, the American Society for Reproductive Medicine (formerly the American Fertility Society) differentiates according to the woman's age - one year of trying to conceive for women under 35, and six months or more for women over 35 (Berger et al., 1995:54). Alternatively, the World Health Organisation (WHO) specifies the period of trying to conceive as two years. As the rates of pregnancy naturally increase over the months spent trying to conceive (Jansen, 1996; Keye, 2000), the definition of infertility affects infertility statistics (Gazvani, Ozturk, & Templeton, 2002). Some argue that twelve months is too short a time to define infertility, resulting in the over-diagnosis and over-treatment of infertility (Stephenson & Wagner, 1993:3). This man, whose wife later went on to conceive naturally after nine years of infertility, said:

> "I don't see infertility as being childless after one year. If it's possible to have a child, then I accept that we keep going." *Arthur*

The New Zealand Department of Health Discussion Paper on Infertility emphasises the perception of infertility as a problem, for those who are unable to conceive (Brander, 1992:7). The American Infertility Association, (RESOLVE & Aronson, 1999:5), describes infertility as both a disease and a life crisis, which affects people of all ages, ethnic backgrounds, socio-economic groups and both sexes, interfering with one of the most fundamental and highly valued human activities - that of building a family. Therefore, infertility is defined according to duration, physical inability and psychological perception as a problem.

> "Infertility is a very real thing. It is not just a statistic. It affects people. It affects a lot of people and I don't think it's something that we should be ashamed about... I think of it as being no worse than being an inability to have cats, because you're allergic to them. It is something that needs to come out in the open... There are a lot of people out in the world that are infertile and for a long, long time it has been sort of shoved under the carpet and forgotten about." *Harry*

Infertility is a label, which is difficult to define. It is both descriptive and prescriptive. Some of these conceptual and methodological difficulties include differentiating between fertility and fecundity; permanent and temporary infertility; and voluntary and involuntary fertility and infertility. (See Appendix 19 on being childfree.) Infertility and fertility can merge into one another, one condition becoming the other as individual reproductive choices and circumstances change over time (Sandelowski, 1990:477). The language surrounding infertility is often defined by lack and sometimes by want, for example, 'infertile' (not being fertile), 'childless' (being without child), 'non-parent' (not having parental status) and 'childfree' (being free of children). A philosophical debate exists about whether infertility is a disease in the usual sense, and therefore whether it belongs wholly to the medical domain of diagnosis and treatment and what role the social and cultural context has for framing the condition of infertility. These questions and perspectives are considered later in this chapter. There is similar discussion about infertility being a disability, which has implications for the government funding of infertility treatment.

> "In as far as disability, I've often thought that it would be much easier to not have a foot or, you know, other disabilities that are obvious... I don't want to have sympathy or anything like that, but it's such a private hurt." *Charlotte*

There are also differing definitions between primary and secondary infertility. Primary infertility is defined as the failure to conceive by women (or couples) who have never conceived, while secondary infertility affects women (or couples) who have previously conceived but who fail to conceive again (Keye, 2000:27). Confusingly, secondary infertility also refers to people who have borne a child previously, but are subsequently unable to become pregnant or have a live child (Simons, 2000:313). For the purposes of this thesis, *primary infertility* will apply to those people who have not given birth to a child, while *secondary infertility* shall apply to those who have been unable to successfully have a second child. Secondary infertility is commonly a neglected, as infertile parents are uniquely isolated and do not get the same understanding or sympathy, as those who do not have any children. Decision-making about infertility treatment is complicated by particular concerns about the existing child - being an only child or having a sibling who is adopted or the result of donor gametes (Simons, 2000:321). The consciousness of time running out in which to 'sensibly' have a sibling is also an issue. Several respondents had only one child and wanted more.

> "Prior to having a child... there was a gap in our lives. I suppose now we have got a child, that bond has been filled. But... Olivia wants another child and... we haven't been able to accomplish that." *Vladimir*

Infertility crosses sexual orientation and relationship status. People who seek treatment for infertility may not in fact be childless or medically infertile, as one or both partners may have a child or children from a previous relationship, or a woman may not have a male partner. Those who are single or in a lesbian relationship, while often not physically infertile, are socially infertile. Historically, it was assumed that single women should not be, and lesbian women were not, mothers (Jacob, 2000:267). Nowadays, both groups represent an increasing proportion of consumers of infertility treatment services, mainly on a self-funded basis. Along with older women and remarried couples, lesbian and single women constitute a swelling social change of those accessing reproductive technologies (Burns & Covington, 2000:19). The single or lesbian woman who is infertile still suffers from the additional burden of being seen by some as less acceptable or deserving of infertility services (Stotland, 2002:18). Several authors present the issues of single women and lesbian couples using assisted reproduction (Baetens, 2002; Boivin, 2002b; Daniels & Burn, 1997; Haimes, 2002; Jacob, 1997, 2000).

Prevalence of infertility

As well as the definition of infertility varying, the prevalence of infertility is also subject to diverse estimates. Internationally, and within New Zealand, it is generally understood that about one in every six couples will experience infertility at some point in their lives (fertilityNZ, 2003a). This commonly cited figure is probably a major underestimate, as the *cumulative* incidence of infertility is cited as 26.4 percent of New Zealand women at some point in their lifetime (Gillett, Peek & Lilford, 1995:1). Approximations of infertility range from 10 to 15 percent in western countries (Tinneberg & Gohring, 1998:49), though it is cited as being as high as up to 28 percent of 25 to 45 year old women, at some point in their lives by Schmidt (1998b:63), again a cumulative figure. However, the percentage of people, at any one time, who have been unsuccessfully trying to conceive for more than twelve months is actually quite low, estimated at about five percent (personal correspondence from fertilityNZ, Sept, 2003). Appendix 14 contains more information from Statistics New Zealand about the prevalence of infertility.

The incidence of infertility is *probably* rising due to the increasing age of women having children and the incidence of sexually transmitted diseases (Adair & Rogan, 1998:263; Diamond et al., 1999:7), and exposure to environmental toxins (Leiblum, 1997:8). Others say that infertility rates have remained surprisingly steady for up to a century (Burns & Covington, 2000:5; Keye, 2000:27), although they may be more visible because of an increase in the absolute numbers of the infertile among married couples of the baby-boom generation (Sandelowski, 1986:440). These estimates do not include single women or lesbian couples who wish to conceive. However, there has been a dramatic increase in the use of medical services for infertility, due to the tendency for delayed childbearing, the ageing of the baby-boom generation and the increasing number of treatment options (Gillett et al., 1995:13). This man notes:

> "We're not the only ones out there... It's almost like every other night you watch TV and there's something on about childless couples or infertility or baby kidnapping." *Murray*

The rates of secondary infertility are also subject to varying estimates, and are affected by the precise definition of secondary infertility. In terms of conceiving a second child, it may be as low as ten percent (Berger et al., 1995:312), or as high as half of all infertility rates (Diamond et al., 1999:9). It may be statistically more common than primary infertility (Simons, 2000:313), or seventy percent of infertility rates, if referring to infertility after a previous conception (Keye, 2000:27). As with primary infertility, aging clearly has an effect on secondary infertility rates. The actual rates of secondary infertility are hidden by the presence of a child in the family and the numbers of infertile parents who actively seek medical help (Simons, 2000:313).

> "Our second child was more a symbol that we were now a family and having two children meant no-one asked you when you were having your next child (but she died)." *Martin*

There are warnings of inflated figures of infertility (Stephenson & Wagner, 1993:2). It is difficult to access precise numbers of people with fertility problems, because of the private nature of the issue. Unless people have a recognised infertility diagnosis, are having treatment, or are adopting (usually with no other children), their numbers are likely to remain hidden. The actual incidence of infertility in the population is impossible to state with any certainty (Leiblum, 1997:9), as Cameron reiterates in terms of childlessness in New Zealand (1997:202). This man expresses a commonly felt sentiment.

> "You hear statistics that there seemed to be ten percent of the population was infertile, then it was twenty percent, now it seems to have climbed to about thirty three and a third... When Anna and I were first involved... I felt that I was pretty unique." *Dillon*

These sheer numbers, about 26 percent of New Zealand women at some point in their lives (Gillett et al., 1995:1), reveal that infertility is a relatively common experience, which warrants our professional and academic attention. Infertility is almost always unexpected crisis (Leiblum & Greenfeld, 1997:83). The experience of infertility brings enormous repercussions physically and emotionally, and for some financially, socially, spiritually, morally, sexually, and professionally (Zoldbrod, 1993:5).

Types of infertility

> "The problem is on my side; you sometimes think 'well maybe they should just go off and marry someone else and have children'." *Debbie*

There are many different causes of infertility, which can be divided into male, female, male/female, and unexplained infertility. Around 85 percent of infertility can be explained. Male problems account for about thirty percent of explained cases; female problems account for another thirty percent; and a joint male/female cause for about 26 percent (WHO, cited in Gillett et al., 1995). Of the known causes of infertility, the most common are ovulatory disorders; abnormal semen; abnormal fallopian tubes; and other problems being linked to the cervix and uterus, immune system; infection, and sexual dysfunction (Keye, 2000:27). The myriad of known contributing factors to infertility includes hormonal problems; congenital problems; infections; scarring; physical blockages; environmental factors; increasing age (Coney & Else, 1999); obesity; heavy smoking or alcohol intake; and vasectomy (fertilityNZ, 2003c). About 15 percent of infertility cannot be explained. Several study respondents spoke of the difficulty of having an unexplained, or ideopathic, diagnosis.

> "We go through all the options. Is it the sperm? Is it the blood? Is it the chemicals inside you or whatever it is could be killing it off. And you try everything... and they say... 'Everything is alright', and you can't understand why." *Dave*

Types of treatments

People experiencing infertility are faced with three options (Daniluk, 2001b122). They can accept their childlessness, pursue alternative parenting arrangements (such as adoption), or seek medical solutions. From the start of last century, women, and sometimes their husbands, have sought medical help for involuntary childlessness (Pfeffer, 1993:1). Assisted reproductive technology (ART) can be defined as the use of medical technology to attempt to achieve a pregnancy (Coney & Else, 1999:13). The recent swift development of new reproductive technologies to bypass or overcome infertility has totally changed the way that conception can take place. Assisted reproduction now includes drug stimulation, surgery, intrauterine insemination (IUI), donor insemination (DI), *in vitro* fertilisation (IVF), intracytoplasmic sperm injection (ICSI), sperm extraction techniques, egg and embryo donation, ovarian freezing, surrogacy, and gestational carrying. These new treatments for infertility have no precedent in history. Infertility treatment offers the significant and attractive possibility of a child.

As this study drew respondents from two infertility treatment sources, donor insemination and *in vitro* fertilisation, it is these treatments, which will now be focused on. Appendix 15 provides more detail on DI and IVF, including success rates, access to treatment and cost.

> "There's no point going into a donor insemination programme if there's no problem with your sperm, so you've just got to know what exactly your problems are and accept them and go from there." *Jade*

Donor insemination: bringing in a third party

Donor Insemination, or DI, is primarily a treatment used for male infertility. It bypasses the actual male cause of infertility by involving sperm donated by a man outside the relationship. Historically, DI is the "oldest of medical interventions designed as a response to infertility" (Daniels, 2002:31). It is also cited as being the simplest, most widely used, least expensive, and probably the most effective form of alternative method of conception (Lasker, 1998:7) and alternative method of building a family (Zoldbrod & Covington, 2000:325). As such, it means that the male partner is not the genetic father.

> "The other negative side for me was feeling a bit sad at times that Jim isn't the natural father and wishing that he was." *Rose*

Like other treatments for infertility, DI requires decisions. These include: where to have treatment; when to schedule treatments; how many cycles to undergo; how many years to try; how much money is to be invested in the attempt to have children; and at what point other options like adoption or not having children at all are looked at. At a more intimate level, within the relationship, informal decisions, such as who will take responsibility for the 'organising' of the various aspects of treatment is required.

However once the initial decision to proceed is made, there are particular decisions to be made with DI, which extend to other third party reproduction. A known or unknown donor must be selected, which could have implications for generations, especially in medical terms. Unless the donor is a family member, 'genealogical bewilderment' (a term which was borrowed from the adoptee rights movement by Cooper & Glazer, 1994) may be experienced. People using donors recruited through fertility clinics need to select a donor based on the presented characteristics. This man wondered about the donor of his child.

> "We are appreciative of donor-type people who make those efforts and... those people must wonder what's happened to parts of them." *Frank*

Disclosure is a major parenting issue - whether to tell the donor child, or not, of how they were conceived is a matter of much debate (Adair, 1998; Adair & Rogan, 1998; Daniels & Burn, 1993; Hargreaves, 2002; Rumball & Adair, 1999). These decisions are influenced by the family structure, family history, and surrounding social context (Burns & Covington, 2000:462). Prior to having DI, there is much attention paid to the issues involving the child's rights to know about their genetic origins. In New Zealand there has been a strong move to encourage parents to tell their donor children of their origins, as happens with adoption in this country (Adair & Dixon, 1998). It is likely that the unique cultural heritage of New Zealand has made this possible, given the importance to Maori of knowing their whakapapa or genealogy. For some parents, the decision is less about whether to disclose to their children of their donor origins, but more the process of how and when to disclose. Decisions need to be made as to what age to tell them, how much to tell them and also when to tell others in their family, social or other circles (Daniels & Haimes, 1998; Snowden & Snowden, 1998). The reactions from others to disclosure can raise particular issues, cause stresses (Vercollone et al., 1997) and create ongoing personal dilemmas for people having DI, as this man relates.

> "Dad questioned the need to tell (our daughter) that she was a donor child, for instance, and... kind of reinforced the generational gap, nothing major." *Jim*

DI decisions may involve the genetic blending of families. Some families may have a fully genetic child, but because of funding or fertility issues then choose to try to have a donor child. For those who already have one donor child and desire another, ideally sperm is available from the original donor. If not, then a second donor needs to be chosen, adding to the genetic make-up of the family. Currently, with the prevalence of IVF using micro-injection techniques, some donor families are then attempting to have a fully genetic child through IVF. This man explains the attraction.

> "This micro-injection I think... for me personally, that's quite exciting. I'm too long in the tooth and too world weary now to get my hopes up about it, but it certainly puts a bit of a sparkle in me thinking about it." *Bill*

In vitro fertilisation: a complex process

In vitro fertilisation, or IVF, is a highly technical process developed originally for women with irreversible tubal problems. In the past twenty years, it has changed from being an experimental procedure to a widely used and accepted medical treatment (Burns & Covington, 2000:8), for virtually all forms of infertility (Keye, 2000:42) including male factor, ovulatory, endometriosis and ideopathic (or unexplained) infertility.

Significantly, it is now commonly used in conjunction with sperm extraction techniques, intracytoplasmic sperm injection (ICSI), donor egg, and donor sperm. In comparison to DI, IVF is complex and demanding. It involves many injections of fertility hormones to produce multiple eggs, which are aspirated out of the ovaries, under anaesthetic. Meaning fertilisation 'under glass', the eggs are mixed with sperm, and depending on fertilisation, up to three embryos are transferred into the woman's uterus. Any remaining embryos of good quality can be frozen in liquid nitrogen for later use by the couple. The public does not generally understand IVF, as this man says.

> "People... probably don't even know what the initials IVF stand for... There are times I'd like to tell the whole world that we've been through the IVF cycle, but at the end of the day it's our business and it's a very private issue that we are very protective of." *Bob*

A higher number of IVF attempts is directly associated with an increased likelihood of success (Dor et al., 1996; Fukuda et al., 2001; Sharma, Allgar, & Rajkhowa, 2002; Roest, van Heusden, Zeilmaker, & Verhoeff, 1998). This influences the decision to continue with treatment. Along with the number of IVF cycles, treatment success is most importantly influenced by the woman's age and to some degree by the cause of infertility. Many male respondents from the study likened the chances of conceiving through IVF to a numbers game.

> "To me IVF is a bit like throwing a six on a dice and until you have five or six goes you can't really say you've given it your best shot. In Australia, one woman got pregnant on her thirteenth treatment and that is incredible." *Paul*

People undergoing IVF are faced with many decisions once the initial decision to proceed is made. These include how many cycles to undertake (in terms of stress, cost, age, side effects and risks); how frequently to have cycles; how many embryos to have replaced; and whether to freeze surplus embryos. Decision-making is complicated by surplus embryos, which are created through IVF (Graumann, 1998). People who have surplus embryos left *after* completing their families have the choice of donating them to other infertile people, donating them to research, or discarding them. Embryo donation raises ongoing ethical, legal and psychological questions (Leiblum, 1997:4), similar to sperm donation and adoption. One man with frozen embryos said that their donor IVF child is:

> "not a plastic baby, not a test-tube baby. And if there's two more of those coming up on the supermarket shelf, then we want to see that they have a good life." *Frank*

Adoption

Adoption is an option for childless couples seeking to have children, and was a successful way of building a family for several participant couples. There are crucial differences in choosing between treatment for infertility and adoption which influence decision-making. Adoption does not cure infertility, but like the use of donor gametes and surrogacy, provides a way to overcome childlessness. Medical intervention is oriented towards creating people's own child (even with donor gametes), whereas adoption services are interested in what people offer someone else's child (van den Akker, 2001). Adoption has been practiced around the world for thousands of years, for reasons of infertility, family breakdown, death and the sharing of children among the wider family. Adoption has changed significantly in the last thirty years, and is now less of a viable option to build a family than it used to be (Salzer, 2000:391). However, it remains an alternative to treatment.

> "There are other options to infertility and IVF... and adoption really is... I was really nervous on the first when we adopted (our son), because I didn't know how I would accept the fact. But it was just an absolute breeze, no problem, so with (our daughter) it just wasn't an issue, in acceptance and experience." *Arthur*

Adoption can be a difficult and confusing choice to make. Deciding to adopt a child is a complex process involving multiple shifts in personal identity and role enactment (Brodzinsky, 1997:249). It is a positive alternative for people who regard 'parenting' to be their key priority, rather than that of being a genetic or birth parent (Johnston, 1994:193). Crowe (1985) reported that women were more positive about adoption than their male partners. While advances in assisted reproduction have complicated decision-making about infertility treatment, they have also complicated decision-making around adoption (Brodzinsky, 1997; Daly, 1988, 1990; Daniels, 1994; Holbrook, 1990; Salzer, 2000).

Adoption is an option before, during and after fertility treatments have been exhausted. Daly (1990) found some people were *sequential*, in that they needed to let go of biological parenthood before identifying as adoptive parents, while others pursue both goals *simultaneously,* as a two-track approach to cover both bases (Diamond et al., 1999:67). One study of IVF couples found that half had already made arrangements to adopt, while another quarter was open to adoption (Callan and Hennessey, 1986). Similar patterns can be found in negotiating infertility treatment decisions. For most, the decision to adopt, or use third party reproduction (donor sperm, eggs or embryos) does not take place quickly or easily, and is often viewed differently within the relationship (Salzer, 2000:396). Almost always, the process starts with efforts to have one's own biological child (van Balen, Trimbos-Kemper, & Verdurmen, 1996) before the choice to pursue adoption is made (Brodzinsky, 1997:249). Given the high demand for adopted children, there are no guarantees of a successful placement.

> "Everybody who is infertile realises that resources for solving that problem are scarce and there is only a certain number of children up for adoption and with all the other things, there's waiting lists." *Harry*

The process of negotiating different treatment and adoption pathways towards parenthood has been called 'mazing' (Sandelowski et al., 1989). Adoption, which may have been previously discarded as an option early during infertility treatment, may be considered more seriously as time progresses. During this emotional and complex process, people usually cognitively reframe their personal ideals of parenthood to be consistent with their practical options. With the decision to terminate infertility treatment or accept that treatment may not work, people relinquish their hope of a genetically related child, making the option of adoption more attractive (van den Akker, 2001:156). Appendix 16 contains information on adoption figures and issues.

Why is infertility a problem?

To answer this, one must look at why people want children. The motivations to become a parent are universal and timeless - influenced by biological drive; cultural norms; religious mandate; status; becoming an adult; love; pleasure; purpose; economic value; ego satisfaction; role fulfilment; and power (Burns, 2000:449; Callan, 1985a:1). "Biologically speaking, reproduction is the ultimate purpose of every living being... The biological imperative to reproduce is reflected in a psychological and behavioural imperative. Infertility frustrates that imperative" (Stotland, 2002:13), as this woman explains.

> "For me, being a wife and mother was a core thing, what my life was all about or going to be all about.... You're often perceived by other people as being a selfish career woman. It couldn't be further from the truth... I still feel like a mum - a mother without children." *Charlotte*

The wish for a child depends on a complex interplay of many factors: individual instincts; personality development; socio-cultural influences; economic factors; personal life changes; interpersonal relationships with partners; and family dynamics (Kentenich, 2002:1). Other pertinent reasons for wanting children may be to please parents; cement a marriage or relationship; prove youthfulness, virility or fertility; have someone to love and be loved by; have someone look after one in old age, become a grandparent; avoid loneliness and regret in old age; and connect to the next generation (Sewall, 2000:419). Infertility research has also uncovered a desire for happiness, well-being, and personal and relationship completion (Halman, Andrews, & Abbey, 1994). Infertile women are seen to place greater emphasis on fulfilling gender-role requirements, while infertile men are more likely to be motivated by the marital completion that children are seen to bring (Newton, Hearn, Yupze, & Houle, 1992). The characteristically long infertility journey triggers a process of thinking and rethinking about why they want to have children, a consideration not usually reflected on in such depth by the fertile population.

> "It has been a really hard part of my life... much harder than coping with the death of our child. I mean that was awful, but as every day went by, the pain could

> get less and at the end of two years, you could smile properly and feel warmth in your heart. But not with infertility - there was always a pain with infertility."
> *Sophie*

As the woman above reveals, the inability to have children is an experience of profound loss and suffering for men and women (Sewall, 2000:411). If at some point in their lives, 26 percent of New Zealanders (Gillett et al., 1995:1), experience a lack of control over such a significant life event and adult role, then infertility is clearly a significant problem in our society, both in terms of its prevalence and also in terms of the debilitating impact it has on people's lives. Infertility's legacy often includes compound losses, including the long-term yearning for a child, intrusive medical technologies, possible third party reproduction, a tenuous, highly anxious pregnancy, and frequently a very high investment of time, energy, and money to have children (Burns & Covington, 2000:449). Infertility is a deeply life-changing experience because it challenges so many fundamental assumptions about how one's life should be (Becker, 2000:206). The issues triggered by infertility have been the focus of much research and writing, reviewed in the following sections.

Identity as infertile

> "The experience of infertility has influenced my identity... in how I see myself... I am different. I haven't gone through the same things as they have."
> *Jade*

The ability to reproduce is central to identity, a sense of adequacy and normalcy, both personally and socially (Stotland, 2002:13). Children provide a 'passport' to a normal mainstream lifestyle (Bartlett, 1994:23). When that ability is blocked by infertility, a fundamental deficiency is created and risks being internalised. As time passes without a successful pregnancy, an 'infertile identity' can take root (Diamond et al., 1999:12). This internalisation of the infertility experience (Olshansky, 1987) involves infertility becoming part of the identity and self-definition of individuals. Infertility is an invisible 'defect' to others, but it is seen to increase feelings of inferiority, difference and spoiled identity (Matthews & Matthews, 1986a; Miall, 1985), as this woman says.

> "You don't want to be treated as someone with a disease, which a lot of people seem to think that if you're infertile, you're a diseased person. Well you're not, you're the same as what they are - it's just that you don't get a swollen belly." *Margaret*

Being an other, or an outsider, in the search for a clear identity (Sandelowski, 1987:151) that is not defined by negatives (child*less*, *non*-mother, *in*fertile, *not yet* pregnant) is challenging (de Lacey, 2001a:14). Involuntary childlessness forces life goals and personal identities to be altered. The transition to non-parenthood is seen as profound as that to parenthood itself (Matthews & Matthews, 1986b). The ambiguity of identity as 'not yet pregnant' (Greil, 1991) leads to allsorts of other decisions being deferred, or balanced precariously between hope for one's future and the reality of one's present life. This includes decisions about career development and even the size of car and house (Daniluk, 2001c). This man initially planned his ideal family house.

> "We built our house for them. We had the right number of bedrooms and we had a big place and we worked out where all the different tree huts and BMX courses and things were to go and then of course it didn't happen - so we sold it." *Paul*

The stigma of infertility

As birth rates decline, children have increasingly been valued (Fox, 1982:10) as emotionally priceless (Burns & Covington, 2000:5). Children can be seen to provide existential meaning, identity and status, while those unable to bear children have been labelled impotent, unfruitful and barren (Diamond et al., 1999:5). Those facing infertility may be less shunned today, especially older women who are known to experience less stigma, stereotyping and devaluation (Lang, 1991) and less regret about their childlessness (Alexander, Rubinstein, Goodman, & Luborsky, 1992). However, some participants equated the stigma of not having children with a disability.

> "It's almost like having a lifelong disability that you have to learn to live with. And what would be normal options in life just aren't available." *Michael*

Procreation is generally taken for granted (Cameron, 1990) and considered to be a natural and central part of heterosexual marriage, gender identity and normal adult life (Baker & Bertenshaw, 2002:2). Stigma is a common experience of infertile women and men, involving feelings of loss, role failure, lowered self-esteem (Burns & Covington, 2000:11) and a sense of exclusion (Franklin, 1990:205). Inadequacies are deeply felt by those who experience infertility, as they are involuntarily inserted into a 'discourse' of infertility. This man talked about the internalised impact of that stigma.

> "We haven't grown two heads! We're still the same people outwardly. And inwards looking... the thought will come up now and next week that we can't have children, but we might not show that openly." *Ian*

Fertility is important for fulfilling cultural norms and social acceptance - infertility may leave a person feeling powerless, inadequate, unnatural, incomplete, or like an outsider. Stigma, and the perception of difference, is the personalised consequence of the social pressure to have children (Hunt & Monach, 1997:191). While clearly relevant for women, stigma is also a key concept for male infertility, as it is common for men to feel damaged, defective, worthless, guilty, sad, lonely, isolated, and stressed (Zoldbrod & Covington, 2000:329). This childless woman recognised the social pressure to have children.

> "Society... expects couples to have children and expects women to want to have children. I believe there is a general sort of looking down on people who don't have children and society is still very much geared around, you know, the next generation." *Lois*

There has been much written on the subject of the stigma of infertility (Adair & Rogan, 1998; Anleu, 1993; Greil, 1991; Letherby, 1999; May, 1995; Miall, 1985, 1986, 1989; Sandelowski, 1987, 1988; Sandelowski & Pollock, 1986). Even those people who achieve parenthood after infertility may experience or fear judgement, isolation, social stigma or shame regarding the way that they became parents (Burns, 2000:468). Stigma is more pronounced in some cultures and religions, where fertility is highly and overtly valued (Sewall, 2000:420). This Pacific Island man explains:

> "It's like having an extension of your tree, where you extend branches from your tree that have been there before and you're putting branches on it and passing on things that you have learnt and things that have been passed onto you. That is very important to me and my culture. To have children is like to have wealth." *Tama*

Infertility: that thief of control

The loss of control that infertile people face forms a significant part of life, both in terms of centrality of identity and duration over the life span (Cook, 1987; Daniluk, 2001a; Diamond et al., 1999; Greil, 1991; McCormick, 1980; Mahlstedt, MacDuff, & Bernstein, 1987; Matthews & Matthews, 1986a; Paulson, Haarmann, Salerno, & Asmar, 1988; Peoples & Ferguson, 1998; Schmidt, 1998b; Woollett, 1985). Along with the loss of fertility, there are multiple losses, both actual and potential created by infertility, which cause grief (Menning, 1980). These losses include: the 'dream child'; a potential relationship; hopes and dreams; future plans; marital satisfaction; self-esteem; choice and control; a belief in the natural justice of life; confidence and security; an unbroken family bloodline (Houghton & Houghton, 1984, call it a fear of 'genetic death'); the parenting role and biological fulfilment; sexual spontaneity and enjoyment; privacy and spiritual confidence; social outlets; psychological stability; positive body image and functioning; the experience of pregnancy, birth and breastfeeding; and for other family members, the pleasure and perceived status of being a grandparent or close relative; (Conway & Valentine, 1988; Deveraux & Hammerman, 1998; Hunt & Monach, 1997; McFarlane, 1990; Mahlstedt, 1985; Ryan, 1993; Saunders, 1998; Zoldbrod, 1993).

> "I've sort of felt a bit of loss of personal esteem, and don't probably feel as fulfilled." *Jim*

Historically, men invested in having children, especially sons, as chattel property and spiritual heirs (Burns & Covington, 2000:5), which still resonates as a loss for some men. Men are also seen to experience a loss of sexual potency with infertility (Lee, 1996). Miscarriage and stillbirth are also primary reproductive losses, which can be experienced more frequently by those troubled by infertility (Conway & Valentine, 1988). These multiple losses are significant, enormously personal and raise complex challenges to be worked through in the long-term, particularly in moving on from infertility treatment (Peoples & Ferguson, 1998:157). Many of these losses are invisible to outsiders as 'silent tragedies' (Conway & Valentine, 1988:49), thus receiving little recognition or support. Appreciating the many personal losses of infertility aids the understanding of why people make the treatment decisions they do. Infertility is equated with having 'no choice' (Monach, 1993).

> "I wouldn't wish infertility on anyone. I think it is such a cruel thing. It is a choice being taken away." *Debbie*

A life in crisis

Infertility is an unanticipated crisis in a family's life cycle (Frank, 1990b:56; LePere, 1988:76). The emotional pain caused by infertility is likened to a life crisis and well documented (Abbey & Halman, 1995; Batterman, 1985; Cook, 1987; Covington, 1988; Daniluk, 1988; Leiblum & Greenfeld, 1997; Menning, 1984; Read, 1995). The crisis of infertility presents a significant hurdle that threatens important life goals and taxes personal resources (Burns & Covington, 2000:12). As a 'decisive moment' (Saunders, 1998:139), many infertile women report that infertility is the worst crisis of their lives, worse than divorce or the loss of a parent (Mahlstedt et al., 1987). Half the women in one study found infertility to be the most upsetting experience in their lives, compared to only 15 percent of the men (Freeman, Boxer, Rickels, Tureck, & Mastroianni, 1985). Depression is a core experience of that infertility crisis, as this woman reveals.

> "While I was badly depressed, there wasn't any point... I was so obsessed and scared. Scared that I might actually do something silly... I get pretty scared sometimes about being left on my own, with Michael being that much older than me... It has not been a choice." *Charlotte*

Becoming a parent is a major developmental milestone, deepening the sense of self, broadening connections to the community and acting as a bridge to past and future generations (Brodzinsky, 1997; Ryan, 1993; van den Akker, 2001). Life is profoundly disrupted by infertility (Becker, 1994, 2000; Greil, 1991). Most people expect certain life events to occur at particular times in their lives, and an internalised developmental clock signals whether this is 'on time' or 'off time'. Events, like parenting occurring within an expected time frame and can be anticipated, rehearsed and managed, without debilitating an individual's capacity for coping, or disrupting their life continuity (Moos & Schaefer, 1986:7). But infertility disrupts this internal clock, as this man illustrates.

> "It is like life being an escalator and all your friends are carrying on the escalator and you have sort of been popped off the escalator at some stage and you just can't keep rolling on continuing like you had planned."
> *Paul*

The focus on stress and coping

A vast body of literature has emerged looking at the stress caused by infertility and how people (usually women) cope with infertility and its treatment (Becker & Nachtigall, 1991; Berg & Wilson, 1991; Berg, Wilson, & Weingartner, 1991; Blenner, 1990, 1992; Boivin, Takefman, Tolundi, & Brender, 1995; Campbell, Dunkel-Schetter, & Peplau, 1991; Collins et al., 1992; Daniluk, 1988; Davis & Dearman, 1991; Domar, 1997; Domar, Broome, Zuttermeister, Seibel, & Friedman, 1992; Domar, Seibel, & Benson, 1990, Dunkel-Schetter & Lobel, 1991; Edelmann & Connolly, 1986; Freeman et al., 1985; Greil, 1991; Laffont & Edelmann, 1994b; Leiblum, 1997; Litt, Tennen, Affleck, & Klock, 1992; Mazure & Greenfeld, 1989; Menning, 1980; Nachtigall, Becker, & Wozny, 1992; Newton, Hearn, & Yupze, 1990; Sandelowski & Pollock, 1986; Sandler, 1986; Stanton, 1991; Stanton & Burns, 2000; Stanton & Dunkel-Schetter, 1991; Wright, Allard, Lecours, & Sabourin, 1989; Wright et al., 1991). The psychological distress literature reports the infertile population, while distressed during specific periods of treatment, is not more depressed or anxious in a clinically significant way (Burns & Covington, 2000; Dunkel-Schetter & Lobel, 1991; Greil, 1997). Nevertheless, as infertility is painful and usually prolonged, anxiety, depression and uncertainty are commonly experienced (Berg & Wilson, 1991; Hunt & Monach, 1997), as this woman acknowledges.

> "I would cope less. I listen to talk-back radio and I hear all these people go on and on about that baby up in Auckland who was kidnapped, but... I could do that tomorrow, no sweat. I heard the really angry feelings, and the only person I felt angry for is the birth mother. I actually began to think I was really wacko, because... everyday I could see myself as the kidnapper. I hate all these solo mothers around. I see them in Brighton, they sit there and they smoke and they hold onto these fairly new babies and I almost want to kick them... I have become a person I don't like." *Norma*

The similarities of infertility to chronic illness have been noted (Burns & Covington, 2000; Diamond et al., 1999; Fleming & Burry, 1988; Greil, 1991; Kirkman & Rosenthal, 1999; Sandelowski, 1987; Woollett, 1985). This is because of the engulfing and constant nature of infertility, marked by uncertainty, which often lasts years (Daniluk, 2001c:157). Infertility is likened to a 'chronic sorrow' (Unruh & McGrath, 1985), in which the pain of loss is not forgotten, but intermittently remembered and mourned, even long after infertility is an active issue (Burns & Covington, 2000:13). This man openly spoke of suffering from infertility.

> "It's a difficult thing to accept, a difficult thing to cope... You can avoid a lot of the real issues that are perhaps cutting up your heart... Maybe that's one of the reasons I do so many hours work. Maybe that's one of the reasons I go to the pub quite a lot - it's easier to do that than come home to an empty house." *Samuel*

Infertility is characterised by stresses that people often find the most difficult to cope with: unpredictability, negativity, uncontrollability (Stanton & Dunkel-Schetter, 1991), and ambiguity (Sandelowski, 1987). However, the repeated experience of treatment failure may be more significant in terms of distress, than the length of time spent in infertility treatment (Boivin et al., 1995). Each treatment is stressful, as this man notes

> "Our relationship is very stressful when Olivia is going through the programme, because... Olivia believes there is so much pressure on her to sort of 'perform' or to get pregnant, and she just gets that wound up, that it's like an atom bomb on legs." *Vladimir*

Gender differences

Perhaps the most inherent ideas about gender, and what it means to be masculine and feminine, are based on our biological roles in reproduction (Deveraux & Hammerman, 1998:63). Research, and the popular literature (Michie & Cahn, 1997) have predictably focused much more on women in the experience of infertility and treatment, than on men (Greil, 1997; Lee, 1996; Newton, 2000). Fertility and femininity are linked - motherhood is central to the female role (Miall, 1986, Veevers, 1980). If parenthood is thwarted, then women are reported to find it more difficult, even if the cause of infertility is male (Andrews, Abbey, & Halman, 1991; Abbey, Andrews, & Halman, 1992a; Abbey, Halman, & Andrews, 1992b; Abbey, Andrews, & Halman, 1994b; Brand, 1989; Bresnick & Taymor, 1979; Daniluk, 1997; Laffont & Edelmann, 1994b; Mason, 1993; Wright et al., 1991), or there is an unknown cause (Daniluk, 1988). It appears that the impact of infertility *is* personalised and internalised in a more intense way for women, exemplified by this woman.

> "Always the purpose was the old tradition - to find someone, to love them, to have children, bring them up, watch them grow up, help them and be very family oriented. For both of us, family matters... That was my main reason for being - family." *Charlotte*

Indeed, infertile women have been found to be more depressed, anxious, frustrated, guilty, and isolated than infertile men (Abbey, Andrews, & Halman, 1991a; Bresnick & Taymor, 1979; Daniels, 1989; Daniluk, 1988; Greil, 1991; Lalos, Lalos, Jacobsson, & Von Schoultz, 1986; Newton et al., 1990; Slade, Emery, & Lieberman, 1997; Wischmann, Stammer, Scherg, Gerhard, & Verres, 2001; Wright et al., 1989, 1991; Zoldbrod, 1993) and suffer from lower self esteem (Abbey et al., 1991a). Treatment stress is also experienced more intensely by women (Collins et al., 1992, 1993; Leiblum et al., 1987; Seibel & Levin, 1987). Treatment failure appears to impact more negatively on women than men (Newton et al., 1992; Slade et al., 1997). However as time passes, these differences tend to diminish (Berg & Wilson, 1991). Women are found to be more likely to define themselves and their future in terms of motherhood (leaving a space in their lives for children), while men tend to look towards their careers as a measure of their success (Greil, 1991; Sandelowski, 1993).

> "A man hasn't got the same pressure on... whereas a woman's role is to get pregnant and have kids. And that is where their worth was. It's changing to a certain extent." *Derek*

There are fewer studies and less popular literature on the impact of infertility on men (Lee, 1996; Mason, 1993; Michie & Cahn, 1997; Owens, 1982; Roy Sherrod, 1995) and only recently has more attention been directed toward the male infertility experience (Newton, 2000:203). However it has been suggested that men and women experience similar emotions concerning infertility (Michie & Cahn, 1997:148). Men's reactions to infertility are more pronounced if there is a male cause of infertility (Abbey et al., 1991a; Mahlstedt, 1985; Zoldbrod & Covington, 2000). Men are socialised to 'get on with life' by involving themselves in other activities (Snarey, 1988; Snarey, Kuehne, Son, Hauser, & Vaillant, 1987). Men are found to use distancing, denial and avoidance to contain painful emotion; avoid losing self-control; and maintain a role supporting their partners; while they are less likely to seek social support or counselling (Deveraux & Hammerman, 1998; Freeman et al., 1985; Lee, 1996; Mahlstedt, 1985; Stanton, 1991; Stanton & Dunkel-Schetter, 1991; Webb & Daniluk, 1999; Wright et al., 1991; Zoldbrod, 1993). Subsequently, men may find it difficult to mourn the many losses of infertility, let go of hope and reach an acceptance of their childlessness (Lee, 1996:72). Men also tend to be more private and isolated with infertility (Collins et al., 1992) contributing to an 'unwanted conspiracy of silence' (Lee, 1996:48). This DI father chose *not* to tell his family and friends about his son being a donor child:

> "There's more hang-ups and bad points to the fact of being infertile - in the respect of worry, not knowing, insecurity, actually just hiding the truth from friends and family." *Vladimir*

Why is it that men and women respond differently? Historically, women were considered responsible for infertility, either physically or psychologically (Leiblum & Greenfeld, 1997:84). As discussed, the social context in which infertile men and women have been raised is different, and women must negotiate the experience of being unable to become pregnant, give birth and have a child (Daniluk, 1997:108). Even menstruation is played out within women's bodies, a graphic monthly reminder of the failure to become pregnant. Infertile women appear to be more committed than their male partners to the goal of having children (Daniluk, 1997:106), to seek out information about infertility (Abbey et al., 1991a; Greil, 1991; Stanton & Dunkel-Schetter, 1991) and to pursue the medical options to achieve this goal (Greil, 1991; Ulbrich, Coyle, & Llabre, 1990; Wright et al., 1991).

Decision-making: the labour of choice

> "There was no other choice if we wanted to have children. It just became a fact of life." *Anna*

The word *decide* comes from a Latin root, meaning 'to cut away from'. Thus by its very nature, decision-making involves loss (Bombardieri & Clapp, 1984:91). Assisted reproduction, in offering an almost endless and tantalising array of treatments to the willing, requires a degree of decisiveness to deal with the choice available - even if it is choosing to defer or to not decide. Infertility forces people to make a complicated and prolonged set of decisions (Reading, 1989) that they do not want to make, and to live a life that they did not want to live (Clapp & Adamson, 2000:523). Investigations and treatment for infertility mean facing decisions that people never imagine beforehand (Daniluk, 2001c:51). Those thrown into the infertility arena are required to work out these decisions for themselves.

> "Knowing what I know now, that if I met somebody at the beginning of their infertility journey, I would say that I really understand their deep desire to have a child... But they have to decide:
> (a) how much of an experiment they want to be;
> (b) how much control they want to hand over to professionals;
> (c) how much, for how long and how far they'll allow themselves to be enticed into the gynaecologists message that you have to try everything in order to feel that you've done everything you can to have a child - that pressure is there all the time;
> and (d) decide what their personal happiness and peace depend upon." *Clare*

There has been relatively little focus on infertility treatment decision-making in the literature (Adler, Keyes, & Robertson, 1991:111; Cook, 1993:38). This is despite a rapidly increasing range of treatment options for people facing infertility since the 1980's, which some see as 'seducing' people prolonging their period of trying (Sutton, 1998:59; Zoldbrod, 1993:6). People are under mounting pressure to make the 'right' decisions that will not be regretted in years to come (Tymstra, 1989). They are likely to face treatment failure, limited public funding for treatment and limited supplies of donor sperm and eggs.

Many 'sequential' decisions (Beckman, 1982:73) make up the complex infertility journey. Infertility decisions are repeatedly required (Frank, 1990b:56), with unknown consequences (Schmidt, 1998b:67). They are decisions that are completely outside the average couple's fertility decisions. Intense personal and relationship stress and conflict is likely to arise when making important decisions, which may interfere with the actual process of making a satisfying decision. The more important the goal, the more intense the stress experienced with decision-making (Janis & Mann, 1977). The greater the personal investment and loss involved in the child quest, the more powerful the need for success (May, 1995:236). There is no 'right' decision (Dyson, 1993:i; Ryan, 1993:157), and often no straightforward path through the maze of decisions. There are also no guarantees in this quest for a child, despite how long and how hard people may try, and how deeply they yearn. There are few situations in life that prepare people for the challenges of infertility decisions. Most are caught unawares, unprepared and under-equipped for the choices and experiences that lie ahead.

Why do people persist?

Infertility treatment is compelling, both to try and to keep trying (Sandelowski, 1991). The arena of assisted reproduction offers a tantalising array of almost endless options are available to those who are determined or desperate enough to keep trying to have a child, and who can afford it. The available literature suggests that the pursuit of medical solutions to infertility is characteristically long and stressful (Daniluk, 1997; Schmidt, 1998a). Commonly people, especially women, tend to over-estimate their chances of success with treatment (Adler et al., 1991; Berger, Goldstein, & Fuerst, 1995; Collins, Freeman, Boxer, & Tureck, 1992; de Zoeten, Tymstra, & Alberda, 1987; Eugster & Vingerhoets, 1999; Holmes & Tymstra, 1987; Lalos, Lalos, Jacobsson, & von Schoultz, 1985b; Leiblum, Kemmann, Colburn, Pasquale, & DeLisi, 1987; Modell, 1989; Reading, 1989), contributing to treatment persistence, even when chances are quite low. This is because having children is valued more highly than a low likelihood of success (Johnston, 1993:31). The drive to persevere with fertility treatment is common, as this man who had tried 17 DI cycles unsuccessfully before moving onto IVF, typifies.

> "Human nature says 'well just one more, this might be the right one', so you change the donor... so you finish up with a 25 foot black man with 20 other kids and hope like hell he might be the one!" *Peter*

There are several motivations for people to persist with infertility treatment. People experiencing infertility are noted as being committed to pursuing treatment (Greil, 1991:98). The hope to have children is fuelled by a determination and desperation (Boivin et al., 2001:1301) to succeed, whatever the cost. Some people cope with ongoing treatment remarkably well. Age and finances also allow some people to continue treatment for many years, although advancing age creates special pressures to condense treatment. For some, having a child is worth any effort (see Chapter Four), despite clear personal and financial costs. Some people feel unable *not* to choose to continue on the treadmill of treatment, while treatments are available and while they have not been successful. Persisting with treatment may feel like a perfectly rational choice to those wanting a child and able to have treatment for infertility. Some people have got through other challenging situations with a positive attitude, so they may have a belief that being positive and persisting is rewarded in the end, as this man spells out.

> "As far as infertility goes... keep going and don't give up hope, particularly if age is on your side. Certainly that message is loud and clear - if you persevere, you'll achieve." *Arthur*

The quest to bear a child can be a pervasive and compelling process for women (Daniluk & Fluker, 1995:43). An 'imperative for action' is more commonly noted in women (Greil, 1991; Woods, Olshansky, & Draye, 1991). This can drive a treatment treadmill sustained by hope, perseverance, endurance, courage, and patience (Herth, 1996:747). Commonly, it is the woman who is unable to 'give up' trying (Leiblum & Greenfeld, 1997:95; Williams, 1988:153) and who initiates another round of treatment (Daniluk, 2001a:122). Women who continue with repeated treatment cycles are noted to be more optimistic about becoming mothers, than those who stop (Callan, Kloske, Kashima, & Hennessey, 1988:369). Some women regard the goal of having a baby as worth any effort, in terms of time, number of treatment cycles, money spent, physical discomfort and emotional strain, as did this DI mother, finally successful after thirty DI cycles.

> "Keep trying and keep going, no matter what. It's worth it in the long run, no matter what you need to or have to go through. The end result far outweighs anything else - don't give up." *Anna*

New medical treatments for infertility act as a reward for trying harder and longer (Sandelowski, 1986:446). Infertility treatment frequently involves *repeated* cycles, which can be successful, but often are not. More cycles and new techniques provide new hope, but also can result in new disappointment (Becker, 2000:174; Wischmann, 2002:25), as people are faced with cumulative failure. Treatment for infertility can be psychologically addictive, because of an overwhelming personal goal to have a child. After unsuccessful cycles, people may demonstrate 'tunnel vision' (Reading, 1989:111), continuing treatment with a 'gambler's' instinct (Fleming, 1994:216; May, 1995:236; Modell, 1989:129). Being in infertility treatment is likened to being a 'junkie' hooked on drugs, being enticed to try one more time and requiring a detox program to stop (Fleming, 1994:219; Solomon, 1988:42). Treatment is very difficult to quit without regrets. As one woman said, "if I stopped, I wouldn't forgive myself" (Valerie). People can feel that continuing on the treadmill of infertility treatment is the only real choice if they truly want a child (Michie

& Cahn, 1997:161). This mother of two, after 26 DI cycles, offered encouragement.

> "I just thought after like 16 times to get (our son), it might give other people incentive. I know if they said to me 'well look, there's one lady here that had 18 times'... that after that many times it's not a dead loss, it can still work." *Joan*

Anticipated decision regret

> "I was talking to (the nurse) one day and she said that I still had one free cycle there and she thought that perhaps if I didn't use it, I might regret it... So we did it and it obviously wasn't successful. But I am pleased that we did it, because I now feel more comfortable in sort of letting go of the whole process... I have really given it a fair shot, and perhaps done more than some people would do." *Lois*

One significant motivator in continuing to try to have a child using infertility treatment is *anticipated decision regret* (Tymstra, 1989), in which choice is influenced by not wanting to later regret *not* having tried a particular course of action (Bell, 1982; Loomes & Sugden, 1982). Under uncertainty, a path of 'least regret' is chosen (Heap, Hollis, Lyons, Sugden, & Weale, 1992:42). Reproductive technologies raise 'the fear of regret of the road not taken' (Braverman, 1997:215). People worry about later regretting a 'wrong' decision (Warde, 1994), in not taking up an available option (Bombardieri, 1981; Sandelowski, Harris, & Holditch-Davis, 1989). They also worry about giving up too soon (Peoples & Ferguson, 1998:159). Eighty percent of women in one study (Tymstra, 1989) did not want to look back in years to come and feel negative about not having tried IVF. The effort of *trying* is what people have control over, rather than the actual outcome of the treatment, as this woman who tried IVF eleven times, said.

> "I just want to say when I give up that I've tried everything... That's my aim, to really give it one hundred percent and then say 'well look, I've got to face it, it's not going to work'." *Maureen*

Anticipated decision regret can be applied to people returning to a previously tried treatment, or moving to a different treatment, with the hope that this new treatment will be more successful (for example, moving from DI to ICSI, or trying IVF with donor egg). Those who simultaneously have treatment and follow up domestic or overseas adoption are also likely to be influenced by anticipated decision regret, not wanting to miss an opportunity, as they try all possible options to building a family within a limited time frame. This sense of wanting to avoid regret in the future is a powerful motivator and is likely to sustain people in having more infertility treatment, such as this woman.

> "If I say now 'stuff it, I'm stopping... a couple of years later, I'll feel guilty that I didn't try... the full length of trying. So I still want to try. If I would become pregnant and it go all right, I would be very pleased. And if it didn't go, then I would think 'well at least we tried and that's it'." *Jan*

The fear of later regrets needs to be addressed before people decide to move on from infertility treatment (Peoples & Ferguson, 1998:177). To avoid feeling regret in the future, it is important for people to feel satisfied that they have done their personal best to have a family. It is found that people are likely to feel better about stopping treatment, if they are satisfied with the effort they have put into trying (Vercollone, Moss, & Moss, 1997:120). Otherwise, a sense of failure and regret makes the decision to end treatment very hard to make (Read, 1995:86). What constitutes a 'reasonable course of treatment' (Gordon & Barrow, 2000:504) is clearly subject to very personal definitions. People do not generally regret using the knowledge of medical science and knowing they have done everything they could to try and have a child (Daniluk, 2001a:129; Daniluk, 2001c:180; Hammarberg, Astbury, & Baker, 2001:380; Tymstra, 1989:207), talked about by several women in the study.

> "The way I felt about this last cycle, I dreaded it. I didn't want to do it and yet I knew I had to because it was the final one and if I hadn't done it, I would always wonder 'what if?'" *Jade*

Conclusion

To be able to understand people's infertility treatment choices, it is important to understand what infertility is, how common it is, and what meaning it holds for people within our society. Treatment for infertility is rapidly developing. DI may hold less appeal for heterosexual couples who seek a fully genetic child through ICSI, but it is increasingly accessed by lesbian and single women, and continues to be a cheaper option for heterosexual couples with male infertility. Increasingly, IVF is being used with other techniques for all types of infertility, with greater success. These two treatments continue to be significant options for those medically and socially infertile. In modern western societies, the personal, very painful experience of infertility takes place within and is shaped by social structures like the family; norms like that of parenthood; and values such as children's preciousness and sense of future they bring. Further information about fertility statistics, the treatments and their success rates, adoption, access to infertility treatment in New Zealand, and pertinent ethical and legal issues are to be found in Appendices 14 to 18. The next chapter addresses the methods used in the study and introduces the participants.

CHAPTER 2

Infertility Treatment Decisions: Methods and Introductions

> "Once more a very pregnant pause, because these are very philosophical questions." *Dillon*

At the start of the research, I was faced with designing a study that accessed people's most personal of thoughts and processes about their infertility treatment decisions - an area that for many is private, sensitive, and taken for granted. In order to encourage and respect participation, I needed to carefully think out the research methods and interviewing style. This chapter reviews the methods used in the study. This includes my personal involvement in the research topic; participant recruitment, research design and data organisation for both the *preliminary* and *main* studies; and the principles and protective mechanisms guiding the ethical issues of respecting the sensitive and private nature of the issues being investigated. The descriptive second part of the chapter briefly introduces the 56 participants in the preliminary and main studies.

The personal is political: researcher as participant

The topic of infertility decision-making was chosen *because* of my personal and professional interest with infertility, and the importance I attribute to people being active with their treatment decisions. Reflexivity is the process of critically reflecting on oneself as researcher (MacGibbon, 2002:42). The research process has facilitated self-reflection and growth both for myself as researcher and influenced the focus of the study and the methodology utilised. It has held out both a mirror reflecting my own life experiences and a map of alternative paths to negotiate, making the present comprehensible and offering directions for the future. My values, personal experience, professional practice and appreciation of the literature as a researcher formed the structure from which the research questions and design emerged (Strauss & Corbin, 1990:36).

To enhance the credibility of research, the 'distance' between the researcher and the research needs to be explicit (Mays & Pope, 2000:51). In partially identifying with participants, (called "conscious partiality", by Mies, 1983), an active, critical and reciprocal relationship between myself, as researcher, and the participants, as the researched, was created. Both become the change agent and the changed, the teacher and the student. I learned and was changed as a result of my involvement in the research process. As a feminist, it was important to break down barriers between researcher and the researched. As a participant in the 'culture of infertility', I shared experiences of the researched as an insider, rather than as purely a professional observer or 'other' (Wicks, 1998). In asking to be trusted to hear their stories and to be entrusted with the keeping and voicing of these stories, I felt there was "no intimacy without reciprocity" (Oakley, 1981:49). At the start of each first interview I briefly shared my personal experience with infertility. Rapport and trust (and possibly the zero attrition rate between the interviews) were clearly aided by participants knowing of my personal involvement with infertility, minimising differences in status, knowledge or power (Grbich, 1999:98), as this woman verbalised.

> "Dealing with someone who has had the same experience, I just personally find you can actually relate much easier and probably just put myself at ease. I feel that we are on the same wave-length and I think it's a definite plus." *Jane*

The multiple involvements or entry points into an area of work or study is worthy of discussion, as little outside feminist writing has explored people's motivations and commitment to their areas (Smith & Noble-Spruell, 1986:141). There is a surprising lack of emphasis on social researcher's lived experience providing a conceptual source (Bulmer, 1979), although it is not unusual for social scientists to research areas of particular relevance to their own lives (Kirkman & Rosenthal, 1999; Letherby, 2002a; Oakley, 1981; Ulrich & Weatherall, 2000; Wicks, 1998). There are both gains and risks in one's personal involvement in research (Strauss & Corbin, 1990) and work (Peoples & Ferguson, 1998:218). Greater depth and speed of understanding and sensitive insights are gained from the researcher's personal experiences with, rather than distance from, the data, often leading to major scientific discoveries (Glaser & Strauss, in Currie, 1988). Commonalities provide inside knowledge, access to information and possible participants, institutional support and a regular opportunity to observe and test out the fit between literature, research findings and client reality. It is possible to achieve a pleasing congruity and coherence, as the different angles coming together to form a specialist knowledge base, which provides for accelerated learning and experience.

However, being so close to a subject may create the risk of taking certain things for granted (for example, the client group and medical model), being less critical and collapsing the variation of lived experience. In addition, participant honesty may be comprised, if the researcher is counsellor. Researchers may also feel freer to disclose a personal experience with participants if they were not involved professionally. Clearly, infertility counsellors and researchers, should not be involved with any cases in which their moral or personal attitudes may interfere with their professional judgement (Gordon & Barrow, 2000:510). Chapter Five addresses the personal-professional overlap with research.

Deciding on method

How the research method is chosen, understood and applied to the research task is critical in the quality of the research outcome. The study was essentially qualitative, focusing on the meanings, experiences and views of people (Pope & Mays, 1995:42) making infertility treatment decisions. Qualitative research has become more commonplace in the areas of health research and technology (Grbich, 1999; Mays & Pope, 2000:50). Being qualitative, it was inductive with generalisations emerging from the complex data, to bring a sense of the story behind the statistics (Briar & O'Brien, 2003:197).

The questionnaires contained a combination of both open-ended and closed questions. The quantitative summary of condensed results from closed questions made for a sharper analysis (Mays & Pope, 1995:111). Validation and illustration are increased by a combination of qualitative and quantitative methods (Strauss & Corbin, 1990). Qualitative data adds a density of information, vividness and clarity of meaning to the analysis, acting as a critical counter-point to empirical methods (Bell & Newby, 1976; Denzin, 1989; Jayaratne & Stewart, 1991; Louis, 1982), and allowing for greater accuracy. However, successfully blending qualitative and quantitative data requires ingenuity, delicacy, and insight (Jick, 1983). Both research methods make a contribution to our understanding of infertility (Greil, 1997:1700).

Interviewing couples

All interviews were held with participants as couples, rather than individually. This was done for several reasons. Firstly, people who experience infertility do so more often within a heterosexual relationship, although there are a growing number of single and lesbian women who are accessing mainly DI (see Chapter One). Couple research can examine how individual preferences and choices combine in joint decisions (Beckman, 1978), allowing for the understanding of power dynamics within the relationship around fertility decision-making (Beckman, 1982:85) - passive, unilateral or joint (Hollerbach, 1980:146). Secondly, women have tended to be the focus of psychosocial infertility research (Stanton & Dunkel-Schetter, 1991:202). While this illuminates the struggle women have with infertility, the impact on men is disguised and the effect of gender on infertility response ignored. Interviews with both men and women can use gender as a socially important variable (Eichler, 1988), providing a useful comparison. Couples usually share the experience of infertility and can be studied as a shared "unit of analysis" (Greil, 1997:1699).

Thirdly, when participants were first recruited, only heterosexual couples were accessing fertility services through Christchurch Women's Hospital. Fourthly, in a purely practical way, interviewing male and female participants together reduces the time the research process takes. Both partners can and were asked alternately for their response to questions.

Finally, ongoing dynamic discussion can be stimulated as the couple hear each other's perception and opinion of the experience they share. These discussions can then be continued afterwards.

However, there are disadvantages to interviewing participants as a couple, rather than as individuals. Firstly, differences are not uncommon between partners. Sometimes one partner has children from a previous relationship, sometimes they have adopted children out. Sometimes infertility is caused by vasectomy or cancer treatment. Sometimes previous relationships dissolved because of one partner's infertility. With couple interviewing, these significant historic personal differences can be minimised. Male and female experiences and perceptions may not resonate with each other (Daniluk, 2001a:131), as this man alluded to.

> "Why are you rolling your eyes at me? I'm sure Anna can write down what she likes. You're allowed to say what you like." *Nicholas*

Secondly and importantly, interviewing a couple alters the power balance and possibly the response given by each individual. Commonly in a couple interview, it is similarities rather than differences that are stressed, except in cases of relationship conflict or high educational levels (Monroe, Bokemeier, Kotchen, & McKean, 1985). The power dynamics between partners may distort individual responses, to reduce potential conflict and distress. This was noticeable in some interviews. With others, conflict, distress and differences were overt. Finally, the follow-up telephone interview dealing with factual questions was usually conducted with one member of the couple, though at times both wanted and did speak to me. Thus, the information gathered was not necessarily representative of the views of both. One couple separated between the second interview and the telephone follow-up and I was only able to speak to the man.

The Longitudinal Dimension

The main study was longitudinal. Calls to rectify the paucity of longitudinal research in infertility have been made by several authors (Beckman, 1978; Black, Walther, Chute, & Greenfeld, 1992; Moller & Follstrom, 1991a, 1991b; Stanton & Dunkel-Schetter, 1991). The two interviews were held an average of 12.3 months apart. Originally it was intended to be a nine-month interval, but several factors intervened, reflecting the movement and unpredictability in the lives of both the researched and the researcher. One couple needed to be tracked down overseas, one couple was interviewed in the North Island after they made a permanent shift, and two couples were overseas when the second interview was planned. Personal circumstances also intervened, necessitating time out from the research.

There was a further period of 16.8 months (average) between the second interview and the telephone follow-up. Thus, the total average time span of the study was 29.1 months. This two and a half year period allows for an interesting longitudinal analysis. Longitudinal research adds a critical dimension to understanding the unfolding and unpredictable process of people's lives, in a way that a one-off snapshot simply cannot do. By building in time as a variable, the study could highlight the movement or stability in the couples' situations, their treatment decisions and attitudes regarding moving on from treatment. This was valuable, as participants' treatment paths and infertility decisions were complex, fluid and dynamic (Beckman, 1982:78) in terms of their direction or pace.

Interview location

Participants were given the choice about where they wanted the interview to take place. Interviews were held in the couple's homes in almost all instances, including one interview held in the North Island. Two were conducted in my office in the hospital, when there were other adults in respondent's homes and they were concerned about privacy. One couple moved overseas between the first and second interviews in the main study. This couple agreed to complete the second questionnaire in my absence. They were sent the questionnaire and audiotape, with instructions, and returned these completed items, without any difficulty.

Preliminary study

At the start of the research process, I was most interested in those people who had stopped infertility treatment. I wanted to know how they got to that point and how they felt about it. This is a poorly researched population internationally and, until now, ignored in New Zealand. The main difficulty in researching people who have stopped or moved on from treatment is that they are largely invisible, not currently attached to any fertility clinic and often want to get on with their lives after the rigors of infertility and undergoing treatment. There is certainly no readily available list of the many people who have stopped infertility treatment. Infertility researchers have drawn heavily on convenience samples drawn from fertility clinic files (Greil, 1997:1699). Otherwise, calls for voluntary participants in infertility research are made through the media.

The preliminary study took place in early 1993 and involved six couples. I used two sources of recruitment: firstly, my own personal contacts who I knew to have experienced infertility; and secondly, those of the Christchurch Infertility Society Committee to access members through word of mouth. Eight couples were purposefully approached, who were understood to have *moved on* from treatment. It was surprisingly difficult to recruit the six couples involved in the preliminary study, because it was hard to track down people who had stopped treatment and who were open to being interviewed.

Unexpectedly, it also emerged that several people in the preliminary study had *not* in fact clearly finished their treatment. While they were recruited openly on the basis that they had stopped infertility treatment and moved on, during the course of interviewing it emerged that a surprising four out of the six couples had *not* definitely stopped treatment. In fact, some of those couples subsequently went back to having treatment. This dramatically demonstrates how difficult it is to turn away from assisted reproduction and the lure of a child. Issues and quotations from the preliminary study are included in following chapters.

Questions for the preliminary study emerged during my professional counselling work, perusing the literature and my own reflections in the area (see Appendix 4). The interviews were conducted in people's homes and discussion around open-ended questions was recorded. Content analysis was used (Pope & Mays, 1995:44) on the two hundred and fifty pages of transcripts, which were physically cut and pasted, to draw out unique and similar thematic patterns of experience and perspective. A summary of findings was sent to the participants along with the transcripts of the taped interview for their information. Results were published in the newsletter of the New Zealand Infertility Society (now fertilityNZ) and presented to the subsequent NZIS conference (Thorpe, 1994), which had generously supported me with a Summer Studentship.

Main study: recruitment

A vital aspect of engaging in research is rethinking ideas and method (Phillips & Pugh, 1994:4). The difficulty I had in the preliminary study of accessing people who had moved on from infertility treatment influenced sampling for the main study. The main study was enlarged to target the more accessible population of people who had undergone (a) at least three donor insemination (DI) cycles; or (b) at least two *in vitro* fertilisation (IVF) cycles at Christchurch Women's Hospital, including active treatment in 1993, or after recent childbirth. Those that lived more than an hour out of the city limits were excluded. Upon recommendation from the Ethics Committee of the Canterbury Area Health Committee, the medical director approved the sample lists and recommended that one couple be delayed or excluded, as they had just lost a pregnancy.

Twenty couples from each of the DI and IVF lists were randomly selected. In early 1994, the medical director of the DI and IVF clinics wrote to these forty couples, introducing the research and myself as the researcher. The proviso was made that future treatment would not be affected whether people agreed to participate or not (see Appendix 5). An information sheet on the study was enclosed (see Appendix 6) with a reply form (see Appendix 7). It was recorded on patient files if people had been approached to participate in the study. Half of those approached asked for more information. This conveniently broke down to ten DI couples and ten IVF couples, making a total of twenty couples. Interview times were set up with all of these people. Therefore, no attrition occurred between those who replied and then followed through with an interview. Of the remainder, twelve couples replied that they did not want further information, seven couples did not reply and one couple were in the process of separating and chose not to participate.

The purpose was to access a group of people who were making active decisions about infertility treatment. As qualitative research with forty participants, the goal was to achieve depth and validity in understanding decision-making, rather than to form statistical representativeness (Mays & Pope, 1995:110). As a self-selected random cluster sample (Pope & Mays, 1995:44), the findings of the study only speak in a true sense about those who responded. The results are of generalised, rather than statistical, value. There was little ethnic diversity (less than the clinic population), although the sample included a range of class backgrounds, which was misunderstood by one woman.

> "Are the people you're interviewing mainly middle-class people?... That's quite sad really, because we've probably got similar beliefs and values and things, so you're going to get the same kind of answers." *Sarah*

No attrition occurred during the course of the two face-to-face interviews and the telephone follow-up. This is mainly due to good interviewer-participant rapport (Grbich, 1999) and persistent efforts to track people down who had moved. In total, seven out of the twenty couples moved between the three interviews, including one couple who went to live overseas temporarily then later moved back to their old house, and another couple who separated after moving to their new home. Four more couples indicated they intended to move before a summary of results was sent out. Motivations for involvement varied, and included helping others, as this man suggests.

> "We were probably quite reluctant to take part in this survey... If we hadn't been fortunate to have children, we'd be telling you to take a hike, because we are

> private people. But we've just got that one hope that if this research is used in some way that encourages somebody to have a go and they are lucky enough - like we've been - then it's worth it." *Bob*

Main study: design

Following the preliminary study, I was also forced to rethink the original method of interviewing chosen. Purely open-ended questions would have been completely overwhelming and unwieldy to use with the much larger sample of forty respondents planned for the main study. The combination of both open-ended and closed questions in the interviews aimed to balance the depth of information gathered with results that were summarised to add to the whole picture of infertility decision-making. During the interview, responses were recorded in two ways - marked on the questionnaire forms and recorded on micro-tape. For standardisation, I wrote all responses on the questionnaire forms, except for one questionnaire that was filled in by a couple who had moved overseas and recorded their own taped responses.

Some of the questions involved answers with pre-coded response options. Particular comments that didn't fit into the existing response options were noted alongside on the questionnaire. Generally participants alerted me to which response applied to them as a short list of options was read. This could involve reading them out a number of times. Flash cards were used in those questions, where there were many options to choose from.

> "They've been good questions, you've put a lot of thought into them." *Maree*

The taped section of the interviews used a number of set questions as a prompt to tease out more complex issues around the infertility experience. Clarification on meaning was required at times. While the respondents' words were faithfully entered under the question asked, transcriptions did not note every pause or 'um', nor did they record the interviewer's elucidations or comments. Therefore, the transcripts are a general, rather than an absolutely full representation of the discussion (Mishler, 1986), while still conveying their intent. The quotations used in the thesis were selected to illustrate particular points of view that were either commonly or uniquely expressed. This man joked about the questions.

> "And where is the Holy Grail hidden? Who wrote these?
> I can recommend a good shrink for you!" *Nicholas*

An interviewer's way of questioning influences a story's production (Mishler, 1986:105). The questions reflected a genuine interest in the participants' ideas, in a mutual search for meaning and understanding of a significant life experience. The questions were devised from a blend of the literature; results from the preliminary study; issues raised in professionally; and personal inquiry. The questions in the main study were enlarged to more generally focus on infertility treatment decision-making, covering the whole treatment path from starting and changing treatments to moving on from treatment. The main sections of the questionnaire were: (a) descriptive factors; (b) treatment choices; (c) living with infertility; and (d) counselling (see Appendices 9, 10 and 11 for questionnaires).

The questions required participants to be aware of their feelings, decisions and infertility history and be willing to disclose this. Interviews can provide a limited source of data, because participants only report their perceptions and perspectives on what has happened (Patton, 1990:245). Clearly, responses are affected by memory recall; personal bias; a simple lack of understanding; the emotional state of the participant; and in this instance a perception that honesty would not curtail their future choices with fertility treatment. Infertility patients' self-reporting has been noted elsewhere as possibly inaccurate because of anxiety (Mazure, De l'Aune, & DeCherney, 1988). Some questions could have a painful resonance, especially for those whose treatment was unsuccessful, ongoing or in limbo, or there were no children. Probably the questions respondents found most difficult centred around: (a) negative aspects of the infertility experience; and (b) purpose and satisfaction perceptions of life. One woman said,

> "I just still find them hard to answer... A lot of them hit on a nerve, even though you think they're not going to... It's only been a year and a half or something since we stopped, so it's still going to be there." *Ann*

The questions were deliberately not given to participants before the interviews. A few participants would have preferred to have the questions beforehand, in order to put some thought into their response.

> "The questions were a little bit difficult to answer on the spot, to be honest... Now whether you want to stop us colluding and contriving answers, I don't know. I have a doubt in my mind whether I've answered them correctly, or you have the right impression." *Murray*

Main study: data organisation

The challenge of qualitative research is to transform vast amounts of data into intelligible accounts (Wolcott, 1994), condense the volume of information, identify significant patterns, and create a framework for communicating the essence of what the data reveals (Patton, 1990:371). To draw out meaning from responses, results were analysed using the following system (developed from Miles & Huberman, 1994)

The relationship between key variables in the study:

- male/female
- IVF/DI
- parent/childless

Those variables that could be, were partitioned or linked:

- DI father/ DI mother/IVF father/IVF mother
- DI childless man/DI childless woman/IVF childless man/IVF childless woman

Respondents (under their chosen name) were linked with a multiple variables identity: male/female; DI/IVF; and parents/non-parents. The closed and open-ended questions used in the questionnaires required different ways of organising the large volume of data. The majority of questions were closed, involving responses of yes, no or various options, with space for further comments. To organise this data, each coded response was entered on a spreadsheet and numbers tallied. Responses were analysed longitudinally over the three interviews, to note consistency or changes in situation or attitude over the two and a half years.

Organisation of the qualitative data was demanding (also aided by Burman & Parker, 1993; Leibrich, 1993; Mishler, 1986; Strauss & Corbin, 1990; Willms & Johnson, 1993). The overwhelming volume of data generated (Patton, 1990:379; Schatzman & Strauss, 1973:97) was analysed using a five-step framework approach (Pope, Ziebland, & Mays, 2000:116) to content analysis (Pope & Mays, 1995:44). 'Familiarisation' involved transcribing tapes into two hundred and fifty pages, then reading and re-reading. A thematic framework was developed, identifying the key issues, concepts and themes by which the data could be examined and referenced. 'Indexing' involved marking and annotating the organised data with descriptive labels, in order to draw out unique and similar thematic patterns of experience and perspective. 'Charting' involved sorting, reducing and reworking the data until a 'matrix system' was developed – consisting of the distilled main responses under each question on one axis and the respondent variables on the other. 'Mapping and interpretation' used these grids, as response numbers were counted both as totals and under variable groupings. This allowed for contrasts and comparisons to be made. Then, particular details were grouped to note general patterns and themes and findings that were predictable or surprising were highlighted. Therefore a way of *quantifying the qualitative* was devised, to systematically draw out meaning from the collective mass of transcripts and at the same time honour the intent of the individual participant.

Ethical considerations

> "Sometimes it's nice to just to have someone like you come along and talk about it, because it makes you think through those things that maybe you haven't talked about for a while and re-evaluate things... If we hadn't done this tonight, then the chances are that you know it may have been days, weeks, months down the track before it ever came up again." *Harry*

Ethical issues in research need to be guided by the principles of respect, beneficence, non-coercion, non-manipulation and justice (Miles & Huberman, 1994:289). Out of these principles, the ethical concepts embraced included: informed consent; confidentiality; competent boundaries; minimizing harm; pursuing truthfulness and avoiding deception; sensitivity; honesty; quality of the research and ownership of the data and its conclusions (Massey University Human Ethics Committee, 1993). The study necessarily involved getting the approval of two Ethics Committees - the Southern Regional Health Authority (which had governance over the IVF and the DI units sampled in the study) and from Massey University. The process of applying to and receiving consent from these two Ethics Committees was very helpful in clarifying ways of negotiating possible ethical hazards, in order to protect the participants, myself as researcher and the organisations involved.

To respect the integrity of these ethical concepts, various steps were taken. The Medical Director of the IVF and DI programmes wrote a letter to a randomly selected sample of patients, asking for participation (see Appendix 5). An information sheet about the study was enclosed (see Appendix 6). Both stated that research involvement was confidential, could be withdrawn at any time, and would not have any bearing on future treatment. Consent forms were signed at the start of the first interview by all participants and myself as the sole interviewer (see Appendix 8).

To assist with confidentiality, participants had both a code number and a name they chose, which were applied to all their transcripts and quotations. The two women typed the preliminary study transcripts knew only the participant's first name. While I had assistance in accessing the names of those who would be eligible for the study, unless these participants told the staff themselves no one knew who was involved. I was the sole interviewer, transcriber and analyser of the main study. Clinic staff may recognise the distinctive stories of certain patients, but they are professionally bound to maintain patient confidentiality. Those in the preliminary study had their audiotapes returned, although this could not be done with the main sample, as the Ethics Committees had recommended that the used micro-cassettes be erased. All participants in the main study received a summary of results (See Appendices 12 and 13).

Careful boundaries were needed because of my overlapping roles to protect: the participants of the study; the clients I worked with; the institution I worked for; the profession I was allied to; and myself in a personal capacity. I introduced myself as having a personal experience with infertility, and answered further questions briefly and frankly. For most participants, this disclosure made a difference to feeling trust and feeling understood, which is discussed in Chapters Five and Six. Given that it was research into infertility, I needed and received the support of several key organisations, The Fertility Centre, and the New Zealand and Christchurch branches of the Fertility Society, now fertilityNZ.

In order to address therapeutic issues as a result of being part of the study, participants were offered free counselling through the Social Work and Counselling Service at Christchurch Women's Hospital. This was to avoid a possible conflict of interest with myself working as IVF counsellor. Respondents were also notified of the existence of the Patients Advocacy Service (see Appendix 6). If participants proceeded to IVF, their involvement with the research project would be discussed at the outset and the choice offered to see an alternative counsellor. However the research contact seemed to strengthen rather than detract from the quality of the subsequent counselling. Multiple points of contact with participants over the two interviews, the telephone follow-up, and with some in a counselling role, was an advantage in terms of familiarity and an ease of relating. The issue of what counselling support IVF respondents wanted was addressed at the completion of interviews. Interestingly, my contact with the IVF respondents as a researcher served to increase my accessibility as an IVF counsellor, and after the first interview several IVF respondents sought follow-up counselling.

> "I thought you were a very friendly, open sort of person and if I had of had you as a counsellor in the beginning, I might have felt more at ease." *Ann*

An ethical issue arose from the questions that focused on the infertility counselling experiences respondents had previously had. The number of infertility counsellors in Christchurch over the last decade is extremely limited and identification of the counsellors was risked - particularly where there was criticism, anger or a lack of connection cited. I have chosen to blur the identity and gender of the counsellor by using (the counsellor) instead of disclosing the counsellor's gender or name. Specific references to me as the counsellor seen by participants have been made transparent.

The research involved time, identification (with me) and emotional risk for participants. Because infertility is a life crisis (Menning, 1980; Mortimer, 1994; Stanton & Dunkel-Schetter, 1991), discussing infertility in an interview can raise painful feelings for participants. To respect the reality that interviews affect people (Patton, 1990:353), there needed to be space for silence and tears, and time to allow the full expression of what people wanted to say. A woman who had wept in the first interview, worried about finding the second interview hard, although she chose to continue.

> "Like today and yesterday, I've been nervous about you coming. I didn't want to have to talk about it and it's so easy just to switch off... Everywhere I looked over the last couple of days there's been children and I wonder if I'll ever get used to it. If I'm honest to myself... I'll never most probably get over it." *Maureen*

It was hoped that participants would gain from their involvement in the study (Munford & Saunders, 2003). Potential therapeutic value exists for participants, as they tell their stories and reflect on their experiences, while being listened to respectfully. There are few opportunities in most people's lives to discuss personal issues in a legitimate and contained situation (Finch, 1984; Oakley, 1981), particularly with such a private and misunderstood experience like infertility. Through this process, participants may have gained insight into their own situations. Interviews may re-open old wounds of grief, but potential exists for the healing in expressing important feelings (Ryan, 1993:21) and overcoming the psychological pressure to be secretive (Patton, 1990:355). Some talked about the second interview assisting treatment decision-making. For example, one man said "How will we decide? After talking to you, today" (Peter). Some participants, who had not sought infertility counselling, had indirectly benefited from the study interviews, as this woman notes.

> "This has made us talk about it, because like we've never really gone for counselling, so you've made us... think of it a bit more than probably what we would have." *Valerie*

The second part of the chapter introduces the participants of the preliminary and main studies.

Introducing the participants in the preliminary sample

In total, six couples were interviewed for the preliminary study in 1993 (Thorpe, 1994). These twelve individuals ranged in age from their early thirties up to their mid forties. Except one Pacific Islander, all were Caucasian or Pakeha. Ethnic identity affects the way people resolve the issue of childlessness (Kentenich, 2002; Molock, 2000; Sewall, 2000). In the case of Maori or Pacific Island cultures, adoption through the extended family is common. The Pacific Island participant adopted from his distant extended family, and he also had two children to another woman outside the primary relationship. Thus in culturally sanctioned ways, he painfully resolved his childless situation.

> "If I told them that Clare couldn't have any kids, they might well say 'you had better leave her and find someone who can'. Or I would get a first born to adopt from someone close in my family." *Tama*

Most of the six couples had primary infertility, not having had children before their experience of infertility (five out of six couples). The cause of infertility varied. Four of the couples had spent more than six years in investigation and treatment of their infertility. Four couples had children - two children were conceived spontaneously, two through DI (one of whom died), two through IVF and one adopted. One other couple remained childless and the other became involved in a long-term foster arrangement, while waiting to adopt. Therefore of those six couples in the preliminary study, most were involved in some sort of parenting. The group of six couples had experienced a wide range of treatment, including surgery, drug stimulation, IVF, DI and IUI. Treatment spending in the quest for children varied from half spending under $4,000, up to one couple spending over $30,000. Infertility was a powerful experience, as this woman notes.

> "You feel like an alien, or something off another planet." *Debbie*

Introducing the participants in the main sample

The main sample consisted of twenty couples recruited through Christchurch Women's Hospital: ten couples who had undergone at least three cycles of DI, and ten couples who had tried at least two IVF cycles. Descriptive factors of the forty respondents include: personal details, family composition, fertility history, and type and cost of treatment undertaken. These characteristics over the three points of contact covering two and a half years are condensed into Tables 2.1 and 2.2, below. Explanations of the different status groups ('active', non-active', 'in limbo' and 'stopped') are found in Chapter Three.

Key to Tables 2.1 & 2.2:

The following tables contain information on participants during the three points of contact of the main study. Interviews *1* and *2* were face-to-face with the couple (18 months apart) and interview 3 was a telephone follow-up a year after the second interview.

Names are the names chosen by participants.

Years are the number of years of infertility at the first interview.

$ Spent is the approximate amount spent on infertility tests and treatment up to each interview. Spaces refer to no money spent.

Cycles refers to the number and type of treatment cycles over the 3 interviews - DI, DIVF, IVF or ICSI. Spaces indicate no treatment since the last interview.

Children refers to children the participants had (childless, or a space, if none), who had them (not specified, if both) and how they had these children - DI, DIVF (IVF using donor sperm), IVF, ICSI, adopted, adopted out or pregnant (not specified, if natural conception) at each interview.

Status is how the couple defined their treatment status at each interview: 'active' if having treatment, 'non-active' if intending to return to treatment after current break, 'limbo' if unsure whether to have more treatment and 'stopped' if no future treatment planned.

Table 2.1 DI respondent characteristics

DI Names		Years	$ Spent	Cycles			Children			Status		
				1	2	3	1	2	3	1	2	3
Anna	Dillon	10	$27,500	30 DI			1 DI child			stopped	stopped	stopped
Mary	Ken	4	$3,500	9 DI			her child 1 DI child			stopped	stopped	stopped
Mavis	Frank	7	$3,500	16 DI 2 DIVF			1 child, 1 DIVF child			limbo	limbo	limbo
Rose	Jim	3	$1,250	3 DI			DI pregnancy	DI child		non-active	non-active	active
Sophia	Peter	5	$8,500	14 DI		3 DI 1 DIVF	his 3 child. childless			limbo	limbo	active
Jane	Bill	8	$25,000	12 DI 3 DIVF	2 DIVF	3 DIVF 1 ICSI	childless		ICSI pregnancy	active	active	non-active
Joan	Joe	7	$7,000	26 DI			his 2 child. 2 DI child.			stopped	stopped	stopped
Elizabeth	Harry	5	$7,500	10 DI		1 DI	childless			non-active	non-active	active
Olivia	Vladimir	8	$4,000	13 DI	1 DI		1 DI child			active	limbo	stopped
Charlotte	Michael	6	$4,000	11 DI			childless			limbo	limbo	limbo

Table 2.2 IVF respondent characteristics

IVF Names		Years	$ Spent	Cycles			Children			Status		
				1	2	3	1	2	3	1	2	3
Maureen	John	8	$28,250	9 IVF	2 IVF		childless			active	active	limbo
Maree	Anton	5	$3,500	2 IVF			childless	adopt 1 child		limbo	limbo	stopped
Valerie	Murray	4	$12,250	3 IVF	2 IVF	1 IVF	childless		adopt 1 child	active	active	non-active
Lois	Derek	11	$3,550	3 IVF	1 IVF	1 IVF	childless			active	active	stopped
Jan	Dave	13	$15,000	2 IVF			her child childless			limbo	limbo	limbo
Ann	Ian	7	$1,000	3 IVF			her child adopted out, childless			stopped	stopped	stopped
Margaret	Samuel	10	$17,000	4 IVF		separate	childless			stopped	limbo	stopped
Jade	Nicholas	10	$12,000	6 IVF		2 IVF	adopt 1 child	adopt 1 child		stopped	stopped	stopped
MaryAnn	Bob	11	$19,000	6 IVF			her child adopted out, 3 IVF children			stopped	stopped	stopped
Sarah	Arthur	7	$1,000	4 IVF	1 IVF		adopt 1 child	adopt 1 child pregnant	1 child	active	stopped	stopped

Ethnicity

All the respondents in the main study identified as Caucasian or Pakeha, several being born in Europe. As a study located in Aotearoa-New Zealand, it was hoped that a more diverse and truly representative ethnic range would respond positively to being involved as respondents. Other research into infertility has also found a predominance of Caucasians (Daniluk, 2001a:123). This bias comes on top of a higher numbers of Pakeha-Caucasian people on infertility treatment programmes, particularly in the South Island, which has a lower population of Maori, Pacific Island and other ethnic groupings. Some findings will have general application to Maori and other ethnic groups, but others will not, due to a unique cultural history, experience and perspective of infertility and treatment decisions.

Age

The average age of men at the time of the first interview was 38.5 and women 35.7. While IVF participants were almost identical in age, DI men were an average of 5.4 years older than their partners. Three DI men were in a second relationship, two of whom had adult children. Age is an increasingly complex factor in people choosing to continue or discontinue infertility treatment, and is discussed further in Chapter Four.

> "I would like to have been a father by the time I was thirty and in our minds it was just the next progression from being married and getting yourself set up, and obviously when that hadn't arrived, we sort of looked to go for treatments." *Paul*

Employment

At the time of the first interview, all of the twenty male participants were employed, three of them being self-employed and the remainder on a salary or wage. Fourteen of the twenty women were employed, again with three self-employed. There were three DI mothers, two IVF mothers and one childless DI woman not in paid employment. Thus, the responsibility of providing financially for the household rested more firmly with men. This DI father talked about his purpose in life partly in terms of his financial responsibilities, to:

> "work and be supportive - full-stop... My basic role in life is to get up, go to work, earn as much money as possible, keep out of trouble, spend as much time as I can with my family, do things around the house... and just be there basically." *Vladimir*

Women were significantly more likely to be in paid work if they did not have children. There were five employed mothers, including one pregnant woman who continued to work in paid employment after their children were born. Nine childless women were in paid employment, some of whom found this difficult because they would have preferred to be full-time mothers, such as this woman.

> "I'm happy with my job, but I don't make it my career... I am still working which I find hard, because I am all ready to give up." *Valerie*

One childless woman wondered if people in less satisfying jobs are more motivated to carry on with infertility treatment.

> "I could imagine that if I was a check-out operator in Woolworth's, the thought of doing that for fifty years would just leave me cold, but in my situation I've got a career, I've got status, I've got a position sort of carved out for myself, which I could quite happily do for fifty years." *Lois*

Cause of infertility

The cause of infertility was predictably male-only among half of the DI group, with the remainder identifying a mainly male cause with some contributing female factors. Two couples moved over to IVF treatment using donor sperm after having a number of unsuccessful DI cycles, and another DI couple were waiting to use IVF with ICSI. Two men had undergone vasectomies in previous relationships and had subsequent vasectomy reversals in the current relationship. Two men were infertile as a direct consequence of having chemotherapy for cancer treatment.

> "It was a choice for us - it was either the infertility or the fact that life may be taken away... So once we'd made that decision, we thought 'that's it, that's behind us. We're now an infertile couple. We'll go ahead and see what other options we can pursue.' *Harry*

Seven of the IVF couples identified a female-only cause of infertility, two other couples had joint infertility and the remaining IVF couple had idiopathic (or unexplained) infertility, following the woman adopting out a baby. These figures compare with WHO statistics of thirty percent of couples having a male-only cause, thirty percent with a female-only cause, about twenty six percent with a combined male-female reason for infertility and about fifteen percent with an ideopathic, or unknown, cause (Gillett et al., 1995).

Length of infertility

At the first interview, participants had spent an average period of 6.3 years for the DI group and 8.6 years for the IVF group trying to conceive after seeking medical help (See Tables 2.1 and 2.2). The time difference between not using contraception and seeking a medical diagnosis was an average of 1.3 years in the DI group and 2.4 years in the IVF group. One IVF couple (Arthur and Sarah) said they had been infertile for seven years, but later talked about having tried for 15 years (hence the variation between the table and a quotation). One DI man had never used contraception and had found out about his infertility 14 years ago, in a previous relationship. He said that with his infertility, he went through "two marriages, I suppose. Two marriage break-ups" (Ken). This woman talked about the prolonged nature of infertility.

> "Treatments always take time - there's no instant solution, there's no instant cure. You've got to wait, wait, wait, wait and go with the flow, go with the process." *Jane*

Amount and type of treatment

The number of treatment cycles varied tremendously throughout the sample. The average number of DI cycles that participants had, up to the time of the telephone follow-up, was 14.9 cycles. This ranged from three DI cycles up to over thirty DI cycles, "for four years almost every month" (Anna). Three DI couples went on to have IVF cycles using donor sperm. One of these couples had undergone eight IVF cycles, seven of which were with donor sperm, before successfully conceiving on the eighth IVF cycle with the partner's sperm using ICSI (intracytoplasmic sperm injection). Before conception, this man had been very excited about the possibility of becoming a genetic father, rather than a DI father. Fortunately, it worked.

> "The only thing that I've really thought about is this new treatment, this new micro-injection, this ICSI treatment. Whereas IVF is all very well and that, it's sort-of left me out in the cold a wee bit, because I wasn't contributing anything at all... The thought that maybe there would be a chance of me doing it... would be magical, would be great." *Bill*

As IVF is more time consuming, costly and invasive, the number of treatment cycles that IVF participants had was predictably smaller than the DI group. The range of IVF cycles averaged 5.3 cycles (including some frozen embryo cycles) and ranged from two up to 11 cycles. Clearly some women are prepared to undergo significant side effects to try and have a baby, such as this woman.

> "The pain part is the part that frightens me more than anything - but I've done it before, I know I can do it again... The pick-up is the start of it. Normally I do get a bit of tummy problem, but from then on I'm in total agony.... I'm hospitalised right through and I'm injected all the time for pain. I can't move, I can't do a damn thing.... I'm so doped up. And it's hard for Samuel to come and watch me... He just sits there feeling miserable, which I feel guilty about." *Margaret*

The amount of infertility-related surgery that respondents had was surprisingly high. Even among the DI group, surgery was more common for the women respondents - five women had had surgery (from one to three operations), compared to three men (including two vasectomy reversals). Within the IVF group, we see a similar, though more exaggerated pattern. None of the men had undergone surgery, though seven of the women had - one woman having had thirteen operations. Four women had a history of ectopic pregnancy, so surgery to remove those tubal pregnancies is included, as with this woman who had experienced two ectopic pregnancies.

> "The... trauma of experiencing ectopic pregnancies, the trauma of going through an *in vitro* fertilisation programme, with all the dreadful things the drugs do to my body, the physical pain I had to experience with

> egg pick-ups and the devastation of a negative result."
> *Jade*

Cost of treatment

The amount spent on treatment varied a great deal. This is over and above any government-funded infertility treatment that participants may have received, and covers the actual financial cost of treatment cycles and surgery to the couple. It excludes fringe costs, such as time off paid work or missed career opportunities because of anticipated time-off work, which are difficult to quantify. It must be noted that these are infertility costs up to 1997, which would be less than today's costs. These figures are approximate, because of the category ranges used and recall uncertainty. I expected the difference in treatment spending between IVF and DI to be greater than it was, as IVF cycles are significantly more expensive. The average amount spent by DI couples was $9,175, compared to $11,255 by IVF couples. Two DI couples and one IVF couple spent over $25,000. Treatment spending can be found in Table 2.1 and 2.2. Details on the costs of infertility treatment and State funding of treatment are contained in the Appendix 15. Cost clearly limited the amount and type of treatment undertaken for some couples, which is discussed in Chapter Four.

> "Some people whinge and moan about the cost of doing a treatment. You can't put a price on a life and if you are both working - why not utilise the extra wage?"
> *Paul*

Family composition

As can be found in Tables 2.1 and 2.2, participants in the DI group were *much* more likely than those in the IVF group to have children - six out of the ten couples had donor children. While three families had one donor child each, the other three were *blended* - consisting of both naturally conceived and donor children, two to previous partners. Another man had three adult children, but was childless in his present relationship. In comparison, only one IVF couple had children. One other woman had a dual fertility status – she had a child from a previous relationship, but was childless in her current relationship.

Surprisingly, *two* out of the ten IVF women had relinquished children to adoption when they were younger. One woman, who had not been able to have any more children said she felt "like a failure, I suppose, because I had a child and I can't have any more" (Ann). The integration of one's sexual history (Deveraux & Hammerman, 1998:87) into an experience with infertility is a challenging process. It is normal to search for a meaning for the suffering caused by infertility, which can trigger guilt and a personal sense of responsibility. The rates of secondary infertility after adopting out a child are higher than secondary infertility rates generally, which raises interesting, though largely unanswered questions about the psychological impact on fertility of relinquishing a child. While no DI couples had adopted children during the course of the study, four IVF couples had adopted, and another two couples were looking at it as an option. To illustrate the advantage of longitudinal study in tracking changes over time, at the second interview, one couple had spontaneously conceived just months after adopting their second child.

> "Fourteen months ago we just had one child... and here we are now with three on the horizon... Four months after you last interviewed us, we had the opportunity to adopt another baby, a little girl and she was born three months after that. And then, when she was... three and a half months old, I got pregnant, after eight years and after five IVFs. So there will be about 12 1/2 months between the babies!" *Sarah*

By the end of the study, about one third of couples remained childless, despite their treatment for infertility. Even this status is complex and can be fluid, as two people had children to a previous relationship, one couple is known to have adopted a child after the interview period and another couple were expecting an IVF-ICSI child. Before this conception, the man said in an interview,

> "it's disappointing not being a father, but what are you supposed to do? Go out and cut your throat, because it's all over? It's not all over. Life goes on. It's disappointing, but to me the only people I have to keep happy in my life is myself and my wife." *Bill*

There are many historical accounts of infertility, death, divorce and remarriage, which are influenced by societal and cultural norms, circumstances and acceptable 'solutions' (Hafkin & Covington, 2000:297). When a relationship dissolves after producing no children, separation represents the dissolution of the entire family, all the dreams they had together, with nothing to show for all the time and energy invested in treatment and the marriage (Deveraux & Hammerman, 1998:184). One childless IVF couple separated between the second interview and the telephone follow-up. They both developed new relationships with partners who already had children, forming somewhat instant, if uneasy families. The man was also open to having his own biological children. Uncannily in the interview prior, he had spelt out their options if they remained childless.

> "Should Margaret and I as a couple not be able to have children, then it leaves us three options. The first one is to adopt.... Our second option is fostering children... If caring for children is the biggest single factor in our life, and if we cannot care for our own children... which can easily be achieved by Margaret and I separating, and her caring for the children of a solo father and myself caring for the children of a solo mother, or me being in a situation where I could conceive my own children with another woman... So it's really the final full-stop on a chapter in our life and the beginning of a new chapter as 'where do we go as a couple?' or 'where do we go as individuals?' and that makes it pretty scary." *Samuel*

Pregnancy loss

Infertility and pregnancy loss represent powerful emotional and symbolic combined losses around fertility, compounding a 'legacy of loss' (Glazer, 1997:243). Miscarriage in the first twenty weeks of pregnancy occurs in twenty to fifty percent of all conceptions; ectopic, or tubal pregnancy in two to three percent; stillbirth in one to two percent of births over twenty weeks; and neonatal deaths in one percent of all live births (Covington, 2000:228). Participants had experienced much higher pregnancy loss figures than the figures above. In fact, *half* the participant couples had lost pregnancies after infertility treatment. Four out of the ten couples in the DI group had experienced miscarriages of donor pregnancies, two of whom had been unable to conceive again.

> "We hadn't sort of told the immediate family (of our DI pregnancy) because my youngest sister was about to have a Christening for her second son... She delayed it about three times over... and the Christening was just after the baby had died. I was still carrying it and we had to be there... About three days later, we went over one night and told them that their grandchild that was on the way had died. They hadn't even known it was inside. Ten weeks - it was enough to have those dreams..." *Charlotte*

Even greater, six out the ten couples in the IVF group had experienced miscarriage or ectopic pregnancy, two couples had one pregnancy loss, another two of the couples each had two pregnancy losses and a further couple had a total of two ectopic pregnancies and four miscarriages. This amounts to a substantial amount of pregnancy loss. Only one IVF couple who had experienced a pregnancy loss had gone on to have a successful pregnancy, three other couples had subsequently adopted children. Two IVF couples remained childless after pregnancy loss, one couple separating.

There are several influences on people's experience of miscarriage, including the length of infertility; the amount of fertility treatment prior to the loss; the financial resources available to 'try again'; the age of the woman and her chances of a future pregnancy; the person's general coping style; support systems (Birdsall, Saunders, & Irwin, 2002:8); and prior history of poor psychological functioning (Covington, 2000b:230).

Conclusion

Looking back over the methods chosen to gather data on how couples made their infertility treatment decisions, a fifty percent initial recruitment for the main study appeared fair, and the one hundred percent participation rate for follow-up interviews proved very successful. Qualitative research methods were found to be appropriate and effective for studying how people make infertility treatment decisions (Mays & Pope, 2000; Pope & Mays, 1995). The method of interviewing provided if anything, too large a mass of insightful data, for which content analysis was systematically applied to draw out themes and patterns (Pope et al., 2000). This data was quantified in part to provide summaries and highlight variable influences, such as gender, parent status and treatment type. The longitudinal nature of the research was invaluable (Beckman, 1978:76) in tracking the changing treatment statuses of participants. Several participants commented on the value of being involved in the research.

> "It's quite interesting reflecting on these questions too, because you tend, as you go along, not to reflect very much on the process." *Rose*

In separating description from analysis (Patton, 1990), the next chapter introduces an original model of treatment status, developed from analysing the movement of participant decision-making over time.

CHAPTER 3

Infertility Treatment Decisions: Stages and Statuses

By conducting a longitudinal study with three snapshots of participant's infertility treatment decisions, it was possible to track the changing nature of those decisions over time. People step on and off the treatment treadmill, re-activate or change treatments depending on motivation, opportunity and the powerful yearning to have a child. This chapter presents an original model of treatment status, to assist in understanding the personalised and fluid nature of people's decisions over different stages and statuses of the infertility treatment process. The model can aid treatment providers to better recognise the treatment status of clients, and tailor support more accurately. This model can help people identify their current treatment status, with its particular nature, commonalities and challenges.

> "She knew that I probably couldn't have kids... I had the reversal... It didn't work and I think that was probably one of the saddest moments, because that is the easiest way to fix things. But then we've had another opportunity with the DI programme... But all that is tinged with a wee bit of sadness, because we are both getting a little older... I really think it would be nice to have a child or two or three or four. I'd have to work till I'm ninety!" *Peter*

Model of treatment status

In carefully unravelling the descriptive stories of participant's treatment over two and a half years, they appeared to fit into four general categories or status groups, and move between them over time (see Tables 2.1 and 2.2). Some authors have made partial reference to different treatment status (Carter & Carter, 1989; Callan, 1988; Daniluk, 2001c; Johnston, 1994; May, 1995; Sandelowski, 1993). The four treatment status groups developed in this model are:

- 'active' for those having regular infertility treatment;
- 'non-active' for those whose infertility treatment is currently on hold while planning to resume it;
- 'in limbo' for those people who are undecided whether they will resume further infertility treatment or not; and
- 'stopped' for those who are not planning to have any further treatment.

The extended time frame of two and a half years saw some respondents continue infertility treatment and others not. Those who did not have further treatment in this time period had not necessarily stopped having treatment altogether. Six out of the ten donor insemination (DI) couples did not have any treatment during the study. Of those four couples that did have treatment during this period, two couples had one DI cycle each, one couple had three DI and one *in vitro* fertilisation (IVF) cycle using donor sperm, and the remaining couple had five IVF using donor sperm and one IVF with ICSI. Similarly, half of the IVF respondents did not have any treatment during the period of contact. Of those five couples who did have treatment over the course of the study, two couples had one IVF cycle each, two had two cycles and another had three cycles. Over the duration of the study, as expected more participants stopped their infertility treatment. Fourteen couples continuing treatment at the start of the study dropped to nine couples by the end. Almost half of these couples were in limbo, undecided on whether or not to have further treatment. Another two couples were non-active because they had a change of family status, either expecting a baby or having recently adopted a baby.

'Active' status

Active treatment refers to those who are having reasonably regular infertility treatment. Any pauses between treatment cycles would be within the expected range of six months for IVF (clinic protocols have a minimum break of three months between IVF cycles) and three months for DI (with which couples can have continuous cycles). As long as people actively pursue treatment, there is always "a possibility their tenancy in the land of the infertile will be temporary" (Daniluk, 1997:121). This waiting during treatment has been called 'not yet pregnant' (Greil, 1991). For most, the pursuit of parenthood through infertility treatment takes up a considerable period in their lives, resulting in significant decisions being kept 'on hold', during the years when people's future parental status remains uncertain (Daniluk, 1991; Mahlstedt, 1985; Salzer, 1991).

People can be active with their infertility treatment in different ways:

- undergoing cycles *continuously* with only the minimum number of breaks;
- having treatment *persistently* over many years;
- trying *parallel* tracks to parenthood, such as simultaneously pursuing treatment and adoption (Sandelowski, 1993);
- *changing* treatment paths from one treatment to another (responding to opportunities such as legal or government funding changes; availability of new infertility treatments like ICSI; or eligibility for free treatment); or
- taking a very *planned* approach as to what treatment they will do and over what period of time (for example, three IVF cycles plus any frozen embryo cycles).

'Active' profiles

There were nine couples who identified as being in active treatment at some time during the three points of contact with the study. This is less than was expected at the onset and means that the other status groups of non-active, in limbo and stopped need to be understood more than they have been. None of the couples stayed active with their treatment for the whole of the two and a half years of study contact. Having active treatment was stressful, as this man describes.

> "I used to get a migraines at the end of every cycle. I'd just feel so sorry for her. Each one you live in hope and then despair. I'd gear myself up and bomb down, and the next day you'd start psyching yourself up. Two weeks and away we go again. It was like going to work." *Joe*

Six couples stopped being active in their treatment because of pregnancy or having a donor or adopted child under one year of age. Three of these couples intended to resume treatment, as soon as they complied with clinic protocols that the child be a year old before re-activating treatment. Two DI couples demonstrated dynamic movement between infertility treatments. One couple had been very active in treatment, having twelve DI cycles, then eight cycles of IVF using donor sperm, before conceiving on their first cycle of IVF using the man's sperm with ICSI. Expecting this child at the time of the telephone follow-up, they mentioned their intention to resume IVF with ICSI, when possible. Another couple expecting a donor child at the first interview, had the baby by the second interview, and planned to re-activate their treatment status when their child turned one. Their decision about further treatment was complicated by choice.

> "We're happy with one child, but we sort of see two children as our optimum number... Because we would both like me to be a biological father of a child, we might take the more risky option of going for number three (with ICSI), which is a bit a luxury really, because we don't... as a family, or emotionally... need a third child... We didn't want to have two children, one of them being biological offspring and one not. And so we decided we'd have two donor children and then both children would know that we valued them enough to have two, if we were successful." *Jim*

The remaining one DI and two IVF participant couples who had been active during the study period all moved in the more predictable direction of having infertility treatment, then giving it up at some point. They moved from being active, to being in limbo, or stopped with their treatment (see Tables 2.1 and 2.2). A woman who moved on after five IVF cycles said that being of active treatment...

> "As you go through them, you realise that you are coming to a point where you have got to make a decision (to stop), and perhaps that's why it gets harder. Physically, it was probably about the same every time - I ended up having about three days off work and everybody would say 'where were you?' and you would have to make up little stories... I didn't enjoy the pick-up part in particular - I really hated that. It's just that you get on a bit of a roller coaster... You've got to get past each hurdle, in terms of producing eggs and then getting them picked up and

> getting them fertilised and then waiting to see what happens... The last two weeks... is the hardest stage, because you have relatively little contact with the clinic too, so you're just left wondering and waiting." *Lois*

In contrast, two further DI couples moved from non-active or in limbo to being active again. These DI couples who moved in this less predictable direction had their reasons. Treatment was re-activated by one couple when the woman changed her employment to permit medical appointments. The other couple were still in limbo about having further treatment by the second interview, but then became very active on account of age pressures. They reactivated treatment to have three more cycles of DI, and IVF using donor sperm, before again changing treatment paths to try IVF using the man's sperm with ICSI (known outside the boundaries of this study). They illustrate treatment 'mazing' (Sandelowski et al., 1989), taking up different opportunities, like free IVF to avoid 'anticipated decision regret' (Tymstra, 1989), illustrated by this woman.

> "Having made the decision that we were more-or-less happy with not having children, now that this other possibility has come up. We're... just trying to decide whether we should look at going ahead trying to have more DI - whether it's just going to put us on the roundabout again, or whether if we don't try it, it's going to nag at us for the rest of our life." *Sophia*

'Non-active' status

People who withdraw from active treatment for a period of time, while intending to resume their treatment in the foreseeable future, are defined as having a non-active status. People who are non-active are taking a *break* from infertility (Daniluk, 2001c:177). By expecting to re-activate treatment, people do not see themselves as undecided about returning to treatment, although they may not have specific future plans. As people move along on their infertility path, it is not uncommon to put medical treatment on hold (Jones, 1996:60), and is recommended by this woman.

> "With the stress and strain of things... have a break now and go back to it in a few months". *Elizabeth*

Breaks can provide a positive time out from treatment, useful to recover emotionally and physically from treatment (Laborie, 1993; Oke, 1999;

Ryan, 1993). These 'sabbaticals' usually occur because people are suffering from treatment exhaustion, being weary with sadness, distress, failure and possibly financially depleted (Diamond et al., 1999:165). Pausing between cycles can take place at any time along the treatment pathway. Being non-active is a way of managing the stress and strain of infertility, controlling the actual time of treatment to suit one's personal situation (Saunders, 1998:145), whether it is stress or change associated with one's job, family or financial situation. Some people plan breaks in order to have a holiday, reconnect with each other, friends, family members, careers or interest - which can be easily neglected while going through an intense course of treatment. They create both a mental and a physical space from the stresses of infertility treatment. This woman said that people going through IVF need:

> "to be strong and brave to carry on... Your body can only take so much and... it's a hellish and hard thing to go through. You're stuffing up your hormones for a while in that month, it can't be good for you... You'd have to give yourself a good break in between times. You just couldn't keep going non-stop." *Margaret*

However, having a break from treatment can be frustrating and seen as a waste of time. There is an urgent sense of time running out as people age (Sandelowski, 1987:157). The pressure of limited reproductive time is compounded by statistics on aging and fertility (see Appendix 14), emphasised by infertility treatment clinics. This makes it more difficult to make rational and satisfying decisions, even though waiting for a few months is unlikely to change pregnancy outcomes drastically (Daniluk, 2001c:73-74). People's time frame and age limit for having children inevitably get delayed as fertility troubles emerge (see Chapter Four), risking becoming an older parent, as this woman in her forties voiced.

> "If you come to fifty, it's still possible. But... you have to think about the child as well, because when you're fifty and you give birth, by the time the child is 15 or 18, you'd be seventy. Well maybe you feel young - maybe you're an old bugger. Maybe you can die and that child has no parent any more." *Jan*

'Non-active' profiles

There were four out of the twenty couples who had a non-active treatment period during the two and a half year study period. These people were having time out from treatment, while intending to resume at some point. They all were non-active in conjunction with being active in treatment, rather than being in limbo (uncertain about what to do next), or stopped (having completed treatment). This indicates the intentional and planned nature of having breaks from treatment.

> "Going away, having other things to think about and a break - it was good and like I said... 'okay, I'm ready to try again'." *Valerie*

Three non-active couples had a break because of a change in family situation and intended to reactivate treatment when their children turned one, to comply with treatment provider regulations blocking treatment for one year after the birth or adoption of a child. A fourth couple were non-active because the woman's work made it very difficult for her to get time off to attend the appointments involved in DI treatment. This was a motivating factor in her leaving that position to become a student, with the flexibility that enabled infertility treatment to recommence.

> "We're not actively, I guess, doing anything to try and get a baby at the moment, because I just feel it would be so much easier once Elizabeth has finished Tech, in terms of caring for the child, without her having to give up anything, or me having to give up anything." *Harry*

Participants were asked whether they had had breaks of more than one year at any point during their treatment - twelve out of the twenty couples had. The birth or adoption of a child caused a period of non-activity for five couples. Stress and depression were given as the reasons for having a break from treatment for four couples (one DI woman had treatment for depression, one couple stopped IVF and adopted, another couple separated and the fourth couple said they needed a break mentally and physically after 11 IVF cycles). Other external factors cited were waiting for IVF to start in Christchurch; not being able to afford private IVF; and waiting for surgery. Spontaneously without prompting, one third of participants (noticeably IVF) recommended breaks between treatment cycles. One man thought changing focus was as important as having time out.

> "A break is not just a time break between the treatments, but some event or something happens in that period of time... Within that time span there is something there that enables you to focus on and divert your attention away." *Murray*

After the space from treatment that a break provides, people either resume active treatment; remain in limbo about what to do next; or move on to other options, like adoption or deciding to live without children.

'In limbo' status

The state of being undecided whether to resume treatment again, or not, is called being in limbo. People in limbo are *stuck* about what they should do. Should they re-activate their treatment or should they leave treatment behind them and move on? This status is marked by persistent confusion, indecisiveness and uncertainty about future plans. Being immobilised by indecision can happen at any stage along the fertility treatment path, and can go on for many years, putting other aspects of life on hold. It is also relatively common, despite being under-recognised in the literature and by infertility clinics. One study of 144 couples reported that significant breaks between treatment cycles were taken by one third of respondents (Emery, Slade, & Lieberman, 1997).

> "You're just drifting aimlessly, not aimlessly, but you're just drifting along. I've got to get some sort of purpose in my life, I don't know what it is. I don't know." *Ann*

What causes this 'decision paralysis' (Bartlett, 1994)? Indecision can occur after years of dashed hopes and multiple treatment failures, leading to people being emotionally depleted and depressed, personally and within the relationship (Newton, 2000:105). It can be caused by disagreement between partners about how to proceed (Salzer, 2000:400); a lack of information about what lies ahead; and not being able to pay for treatment. People are often reluctant to make decisions, using 'defensive avoidance' (Janis & Mann, 1977), especially with emotionally fraught issues such as infertility. Some participants found talking about their infertility, and making decisions, too painful and difficult. Some found it easier to avoid discussion, putting infertility into the background and getting on with other aspects of life. Not making a decision sustains the illusion there is a perception of choice (Bartlett, 1994) and protects one from the immediate impact of loss (Bombardieri & Clapp, 1984:91). Hope is a powerful emotion, which is passively maintained by being in limbo, however unlikely pregnancy may be. The last treatment cycle can be delayed because people can view it as the final door closing on their chances to have a child (Emery et al., 1997:601). People may fear that final decisive outcome, in terms of their own personal futures and mental health, and at times in terms of the future of the relationship, as this man says.

> "Until you actually make the final decision not to proceed, you've still got to think of it as an open option, as it possibly working." *Michael*

Being in limbo is not a surprising response to the stress, distress and uncertainty of infertility and treatment. Ambivalence has been described as 'normal' in the early stages of deciding to stop infertility treatment (Bombardieri, 1993:381). The state of limbo is functional *if* it gives people time experience for themselves what it is like not to have treatment. It can give people the opportunity to quietly try out stopping, without defining it as such, and without removing hope. Time is a useful factor in personal adjustment and decision-making. A period of ambivalence creates a period of time out to reflect on what has happened and reach agreement on what to do next. This 'transitional' period enables people to be open to different possibilities (Bartlett, 1994) such as the options of further treatment, adoption or living without children. No door is closed. Being in limbo can hold value in the short-term.

However, chronic infertility drifting can be maladaptive (Carter & Carter, 1989; Peoples & Ferguson, 1998:178; Sewall, 2000:415). People may not be able to decide to end treatment, decide to adopt, nor decide to live childfree. Difficulty and delay in making infertility decisions can be a warning sign of deeper distress (Clapp & Adamson, 2000:517). Being in a prolonged state of limbo is stressful, compounding the lack of control and choice that accompany infertility. As Freeman & DeWolf state (1989:83), "when you do nothing, nothing happens. Nothing changes." Non-decision-makers are likely to feel they are victims, rather than masters, of their own fates (Bombardieri, 1981). Limbo can lead to a poor self esteem, low energy, depression (Lecocq, 1997), compromised relationships, feelings of unfulfillment and not belonging, lack of direction, and being unable to make other life plans. Ultimately, the decision to move out of limbo can made passively, indirectly or from external sources, such as advancing age or not fitting in with medical criteria, rather than people exerting any choice or control. 'Decidaphobia' commonly leads to a choice being made, without any *conscious* decision (Dyson, 1993:59). These 'passive' decisions (Hollerbach, 1980:146; Oakley, 1986:250) can occur when people in limbo eventually have a decision made for them (Beckman, 1978:64; Berger et al., 1995:279) by other factors, such as aging preventing conception or eligibility for treatment. Not making a decision can indirectly influence outcome, as opportunities pass by.

> "I don't think we actually decided (to be in limbo)... The decision part was going to be hard - to definitely stop or definitely go on. The indefinite happened by default almost." *Charlotte*

'In limbo' profiles

Being in limbo was surprisingly common within this group of participants. During the study, there were eight out of twenty couples, or *one third*, who identified as being in limbo, unsure about whether they were going to have further treatment or not. None of the four couples remaining in limbo by the last interview had any stated time frame in which to make up their minds or indeed resume active treatment. This is of concern, as it shows that a number of couples are stuck for years, not knowing what to do, whether to re-start treatment or finally stop. These people are archived in clinics and are not likely to receive support or guidance from clinic staff, whose priorities are those people in active treatment. The important issue of supporting people in limbo is discussed in the chapters that follow. In particular, two DI couples and one IVF couple were in a perpetual state of limbo for the *entire* two and a half year duration of the study. They provide valuable and interesting examples of being in limbo.

> "As we haven't made the final decision... life is still a bit in limbo - you can't fully commit yourself to something." *Michael*

The first DI couple had undergone eleven DI cycles prior to the first interview, and had been unable to agree whether to have any more cycles, or move on from treatment since then. The woman wanted to re-activate treatment, but the man did not want to. They were stuck and did not know how to resolve this important issue. They found discussing infertility very painful, which meant that making decisions was put on hold. The woman had experienced clinical depression, compounded by infertility and indecision. As she says, one reason people stay in limbo is the difficulty in finally abandoning treatment and the hope of having a biological child.

> "Until there's that finality, there is still hope... But there is also the limbo and that is also hard on us. We don't know where we're going." *Charlotte*

The second DI couple already had two children by the time of the first interview, one naturally conceived and the other conceived on their second IVF cycle using donor sperm, after having 16 unsuccessful DI cycles (following infertility from chemotherapy). Having a number of stored embryos, potential full siblings of their second child, created their dilemma. The couple were directly impelled to moving from being in limbo to becoming active, after the clinic introduced an annual embryo storage charge. The couple felt 'responsible' for the embryos (Haker, 1998), and thought of the embryos "belonging to them, sitting in the tank of liquid nitrogen up at the fertility clinic" (Frank). The frozen embryos were seen

> "like two people waiting up there for me to collect them almost. I just feel as though I really need to get them, or at least give them a chance of, you know, growing into babies." *Mavis*

The third couple lived with the woman's child and had been trying unsuccessfully to have a child together for 13 years. IVF was their only way of conceiving, following two ectopic pregnancies. The woman's age of 44 was not perceived to be a limitation, and she wanted to continue trying to have a child until she was 48 (Jan). Interestingly, the couple had *not* actively pursued the treatment they were entitled to. At that time, they could have had a third free IVF cycle prior to the first interview, including donor eggs with publicly funded IVF, if required. Because they did not want to listen to doctors, they were unlikely to access clinic resources in the form of information about their options, support and medical advice. While they stayed in limbo and didn't act, their goal of having a baby together was likely to remain elusive.

> "It's always in your mind and you're always trying, but... I never accept it, so that's why I never want to give up... The only thing is we've been harder and tougher... And we don't take any bull. No crap from any doctor!" *Jan*

Four other couples were typically in limbo for one or two interviews, then moved in the more predictable direction of stopping by the telephone follow-up. Thus, a period of being unsure about whether to have further treatment sat between a period of active treatment and stopping treatment. As long as this period does not stretch out for too long, immobilising and debilitating those in its grasp, being in limbo can have a functional role in infertility treatment decision-making. One further couple moved in the less likely direction of being in limbo for the first two interviews becoming active by the telephone follow-up. As discussed in the active status section, they had new opportunities, after surgery improved the woman's chances of pregnancy and they were able to access free IVF. New treatment methods extend people's hope in achieving their dream of a pregnancy, making it more difficult to abandon treatment. This is also explored in the next chapter.

'Stopped' status

Those people who have stopped treatment are clear, individually and jointly, about having completed their infertility treatment. They have abandoned treatment and moved on to a different stage in life. Even if a period of confusion or ambivalence occurs beforehand, it means *consciously* stopping infertility treatment, redefining family and grieving the lost experience of a genetically shared biological child (Burns & Covington, 2000:20) and infertility's multiple losses (see Chapter One). Infertility treatment ends for all at some point, due to age, financial, health or interpersonal considerations (Leiblum, 1997:14). This significant decision and the transition that leads on from it, tend not to be recognised or celebrated (Cooper & Glazer, 1994:133). This is because of its private, prolonged and painful nature. The future after stopping infertility treatment varies greatly. People make a decision to stop either after unsuccessful treatment, or after having a child through treatment, naturally or through adoption (Read, 1995:72), as this woman did.

> "Infertility is probably not an issue now, compared to what it was then, because of (our son)... We've sort of forgotten about it... It's more like a closed book." *Maree*

Stopping infertility treatment can be a prolonged, arduous and ambivalent process, compounding the enduring and difficult nature of infertility. It is very hard to know "when you've done enough, when you've had enough and when you can walk away without regrets" (Daniluk, 2001c:179). When is it time to abandon treatment for infertility and relinquish the hope of having a biological child? (Braverman, 1997). Because of the uncertain, open-ended nature of infertility (Greil, 1991:9), there is usually no clear-cut boundary between trying and stopping to try. This is demonstrated in the long periods some participants had being non-active or in limbo. The decision to stop infertility treatment may occur over several days or several years (Sewall, 2000:421). Sometimes, still hopeful, people slip back into treatment for a brief time before eventually letting go (Glazer & Cooper, 1988:147; Peoples & Ferguson, 1998:154).

> "Then you have to quit. You never accept it and you're never satisfied that it doesn't work and you never accept it that it doesn't work and you never accept that you have to go on with your life, but you do." *Jan*

Terminating treatment without having fulfilled the goal of parenthood is particularly challenging (Boivin, 2002c:53). Paradoxically, the treatment that may possibly provide the solution to people's childlessness, is the same entity that inhibits the resolution of their grief (Greenfeld, 1997:43). Relinquishing medical treatment is a powerful symbol of letting go the active hope for a pregnancy (Saunders, 1998:153). Stopping treatment can be seen as giving up and admitting failure (May, 1995). The turning point is the realisation that events cannot change (Read, 1995:78). This 'discrete point' of readiness involves confronting and accepting the permanence of biological childlessness and moving toward a life after infertility (Daniluk, 1996:93), while giving up the dream for a genetic child (Braverman, 1997:209). It also means living a life that runs counter to conventional social expectations (Diamond et al., 1999:182; Peoples & Ferguson, 1998:172) and may run counter to the reality of many friends and family. Some feel overwhelming despair at ending fertility treatment without biological children (Vercollone et al., 1997).

Reorientation to a life without children after stopping treatment is often more difficult for women, than for men (Vercollone et al., 1997:126; Diamond et al, 1999:172). Some women may need help to stop pursuing medical alternatives for infertility (Braverman, 1997; Conway & Valentine, 1988; Daniluk, 1991, 1997; Jones, 1996; Zoldbrod, 1993). This 'permission' to stop may either come from: a partner, because women can feel responsible for bearing a child (Becker, 2000:215); a medical specialist, putting parameters on treatment if chances of success are poor (Daniluk, 2001a:128) or if treatment places people at high risk physically or psychologically; or a counsellor assisting in the process to move on from a different phase (Carter & Carter, 1989; Crawshaw, 1995; Sewall, 2000). This woman who did not know how to stop trying for a child said,

> "I am still wanting to go and go and go. And it will always be in the back of my mind that, yes, I do want to try and still push myself a bit more. They'll probably literally have to stop me, because I think I'd still want to try and I suppose it will be Murray that will turn around and sort of say 'right, we're going to go off and do this', and take me away from it." *Valerie*

Decision-making about moving on from the treatment treadmill is a complex process for both individuals and the relationship. As discussed in Chapter Five, most people make this significant decision on their own, on their own way and at their own pace (Cooper & Glazer, 1994:118). It is informed by a myriad of factors, including financial, medical, emotional and relationship issues (Braverman, 1997). This also emerged in the study, particularly with childless participants. Up to half of all couples who finish infertility treatment do so without a child, and even those who 'move on' from treatment as parents, the infertility experience and identity do not suddenly cease (Daniluk, 1997:120). While there is relief when the physical process of examinations, medications, scanning, inseminations and surgery stops, there is the challenge of confronting the reality of that infertility experience and how life 'is'. This future is often not the one anticipated and hoped for. However, people generally feel that their infertility treatment and their personal investment in trying to have their own biological children are essential before moving on to consider other parenting options or to begin filling their lives with other creative ventures (Daniluk, 2001a:130). While infertility treatment is stressful, prolonged is uncertain in outcome, undergoing treatment can assist people to come to terms with their infertility, as this woman says.

> "I needed to go through the process of some of the treatments. I needed to have information about my body and I needed to know why my body wasn't physically able to conceive... I needed to hear from other women who had been through what I had been through. I needed to hear the effects it had on their lives and relationships and then with all that information, I needed to ask some questions of the professionals involved in working with my body so that: (a) they were reminded that they need to consult with me before they did anything; and (b) that I had some control over the treatments. So I think that was all part of my coming to terms with infertility." *Clare*

'Stopped' profiles

While it was the original intention of the preliminary study to target people who had stopped their infertility treatment, the aim of the main study was broadened to access people who had undergone a number of treatment cycles. It emerged that just over half the participants (eleven couples) had stopped their infertility treatment by the end of the two and a half year research period, allowing for their perspective and experience to be included. Only one couple out of those eleven who had stopped, later changed their minds to say they were in limbo. Generally over time, participants' direction in treatment is predictably towards stopping treatment and staying finished, as this woman pointed out.

> "Everybody reaches a time, or they would have to reach a time, where enough is enough... You know when your time is up and you can't take any more. You just can't continually keep hitting your head against a brick wall, if it's not going to happen - as you'd just go insane." *Jade*

Having children was clearly found to assist in the process of stopping infertility treatment. In fact, eight out of the eleven couples who had stopped by the end of the research period had children through treatment, adoption or natural conception. All four DI couples who had stopped treatment were successful in finishing their treatment with donor children. Three families had one DI child and another had two DI children, after between nine and thirty DI cycles. In contrast, only one couple out of the seven IVF couples who stopped by the end of the study had actually been successful with their treatment, having three children. Three out of the seven stopped IVF couples had adopted children, one of those couples also naturally conceiving a child. This left three IVF couples childless, including one woman who had adopted out a child when she was younger. Stopping infertility treatment without children is particularly challenging, noted by this DI father.

> "It must be real tough if you're continually unsuccessful and you would have to get to the point where you're not comfortable about making the decision to stop treatment." *Frank*

One couple, who claimed to have stopped treatment at each interview, then had two further IVF cycles between the second interview and the telephone follow-up. They were living overseas at the time and were able to have two IVF cycles at a very subsidised cost. This couple were flexible in their infertility treatment planning and decision-making, responding to the *opportunity* for low-cost treatment. There were five couples who moved from active treatment, or being in limbo, to stopping treatment. Two of these couples stopped directly after being in active treatment, suggesting they were following a conscious plan to move on from treatment at a certain point. The three other couples stopped after being in limbo, suggesting that a period of uncertainty about future treatment is not an uncommon component in the process of coming to terms with moving on from treatment, as this man said.

> "You've got to have a point where enough is enough, because it's very stressful and I think you probably put your life in limbo... an obsession." *Michael*

By the second interview, there were 14 people who had clearly stopped infertility treatment. The most commonly cited response to open-ended questions about having moved on was that of *relief* (also cited by Daniluk, 1996). Three quarters of stopped participants felt relieved, including all DI respondents and all IVF men, except one (who said he had accepted being childless). In contrast, only one IVF woman (an adopting mother), said she felt relieved after stopping treatment. It was surprising that the other three IVF women did not feel relieved after treatment stress had ceased, even the woman who had three children. The woman below felt more relaxed since her decision to quit treatment.

> "I don't seem to get upset as much when little children or new babies come in... I always did, now I don't. It's just a lovely little child and I hold it and cuddle it and give it back without any tears - whereas before I was always crying." *Margaret*

Feeling comfortable with the actual *timing* of stopping treatment was a factor for one third of participants who had stopped treatment. Timing is significant in how satisfied people feel with their personal efforts to overcome infertility and their readiness to stop trying. In fact, no one felt they had reluctantly stopped, including those who had no children, or no genetic children. Two women said they felt very lucky to have the children they did. One adopting couple felt frustrated with the failure of treatments to bring them a genetic child. One woman, who had a nine-year history of unexplained secondary infertility, still held hope for a natural conception, after finishing with treatment - demonstrating the enduring power of hope after treatment is relinquished. However, the greatest number - almost half, and particularly women who had stopped IVF - said that they were now able to *focus on other things* in their lives and move onto a different stage in life after the uncertainty of infertility treatment.

> "It's the uncertainty of the whole thing... You think 'now because I have to go on the programme, well I

> might get pregnant'... It makes it very difficult to think and plan long-term. The last five years have been dominated by this... (Now) it's quite good, because you can look forward and plan." *Lois*

Conclusion

Infertility treatment decisions are personal, fluid and emotionally powerful. The longitudinal nature of this study was invaluable in uncovering the patterns of people's treatment decisions over time. This model provides a framework with which to understand and analyse the status and movement of people having infertility treatment, as opportunities and situations change in people's lives. Rather than collapsing the varied infertility treatment experience under active treatment or stopping treatment, this model draws attention to the two treatment statuses that often sit in the middle - being non-active and in limbo. The state of limbo reflects how people are caught between the uncertainty of treatment outcome and the painful process of stopping treatment without the children one wants. Discussion on these different treatment statuses is continued throughout the thesis. The next chapter focuses on the factors that influenced participants in their decisions about infertility treatment.

CHAPTER 4

Infertility Treatment Decisions: Influences and Processes

The focus of this thesis is how couples make infertility treatment decisions and this chapter is central to the discussion. I was interested in the factors influencing people's decisions to start, continue and stop their infertility treatment - what conditioned their choices? The chapter outlines the main results from the three questionnaires, spanning two and a half years of participant experiences, thoughts and feelings, highlighting particular patterns of decision-making found. Respondent decisions are reviewed, from the beginning when infertility was diagnosed, running through the various treatment paths, until a decision to stop treatment was made, either with or without children. The factors that limited treatment use for people and how these changed are discussed, along with the key components participants identified as helpful for infertility decision-making.

> "You tend to do whatever you have to do to get from where you want to be, and with infertility, you just always do whatever is required." *Paul*

Starting treatment

What decisions do people make at the start of their infertility journey? People, both before and after an infertility diagnosis, expect that pregnancy will occur at the desired time with a good outcome (Daniluk, 2001c:52). Unless people have prior knowledge about their infertility, such as from cancer treatment or vasectomy, rarely do they imagine needing to resort to treatments like donor insemination (DI) or *in vitro* fertililisation (IVF).

> "We never really thought about what we wouldn't try, just a step at a time. And I suppose at the time we would never have imagined ourselves considering IVF, but eventually we did." *Stephen*

In the very early stages of the infertility journey, most decisions revolve around diagnostic testing (RESOLVE & Aronson, 1999:261), medical options and proposed treatment path. Infertility diagnosis can blend imperceptibly into infertility treatments (Stotland, 2002:18), as people use medical assistance initially to find a reason for not conceiving, then to help them conceive. This man discussed the progression of conscious choices.

> "Initially, we started thinking 'infertility' when we found out that we weren't able to conceive naturally. That would have been decision number one. Number two was certainly the options given to us... We were told there was a good chance that it would work. It was a natural progression from there, to what was offered to us and our options." *Anton*

Once infertility is diagnosed, do people make a conscious decision to start treatment? Given that this sample was drawn from those who had undergone infertility treatment, it is not surprising that all, but three participants, made a *conscious* choice to embark on infertility treatment. This result is supported by decision-making literature, in which there is an initial conscious recognition of a problem, leading to information gathering and evaluation of choices (Beckman, 1978; Janis & Mann, 1977; Oakley, 1986). If the sample had targeted those who did not proceed with treatment, fewer people may have made a conscious choice to start treatment (see Appendix 19 on being 'childfree'). After choosing to embark on treatment, people generally follow a well-trodden path with variation occurring more in length, than in which treatments are tried.

> "We make a decision that it's time to try again and once we've made that decision, then really nothing else is up to us to decide... Hand our hearts and souls over to them and the rest of the decision-making is up to them and how long and what course of treatment." *Samuel*

Gender motivation for treatment

What is the influence of gender on the decision to start infertility treatment? To proceed with infertility treatment, the two partners in a relationship need to reach some sort of agreement (Beckman, 1978:70). However, this agreement can be based on equal or differential power and motivation. Active decision-making can unilateral or joint (Hollerbach, 1980). Unilateral decision-making recognises that one partner holds more power, often normatively prescribed, in certain spheres. Joint decision-making is the result of consensus or real agreement. Infertility is non-gender specific, affecting both men and women. However, a social and historical imperative exists for women to become mothers and to assume reproductive responsibility (Becker, 2000; Burns & Covington, 2000;, Daniluk, 1997; Greil, 1991, 1997; Michie & Cahn, 1997). As discussed in Chapter One, regardless of infertility cause, treatment focuses on women (Daniluk, 1997), reflecting the physical location of conception, pregnancy and birth in women's bodies (May, 1995), recognised by this man.

> "Most of the time I felt, and I still feel, that it was her body going to have all the changes and have all the tests and have all the things done to it. The decision was like eighty-twenty. Eighty percent of it was hers and only twenty percent of it my decision." *Tama*

What emerged in the course of interviewing about the role of gender responsibility dramatically and predictably demonstrates these factors. Women are *much* more likely to initiate and sustain the momentum for infertility treatment than men are. Almost three quarters of all participants the first interview said that the woman took on the responsibility of initiating and sustaining treatment motivation. No respondent identified the male partner in this treatment motivator role at all. Women are recognised in the literature as the primary motivated decision-maker (Abbey et al., 1991a; Daniluk, 1997; Frank, 1990b; Mason, 1993; Webb & Daniluk, 1999). Women have been described as infertility contractors, taking on the responsibility of stage managing their treatment careers, and exercising more influence that their male partners over the pace and direction of the treatment process (Greil, 1991:86). It may be important to normalise gender specific roles, without interpreting the male partner's lack of initiative in this sphere as resistance to parenthood (Zoldbrod, 1993), spelled out by this man.

> "Sarah initiated the idea and I agreed - there was no problem there... We wanted to have children and we both knew that we should do that because... we had been trying for some 15 years at that point." *Arthur*

Table 4.1 below shows the motivation to initiate and continue treatment within the couple's relationship, by treatment group at the first interview.

Table 4.1 Gender motivation for treatment by DI or IVF:

	DI (n=20)	IVF (n=20)
Female	10	18
Joint	10	2
Male	0	0

As can be seen, there were surprising and marked differences between DI and IVF participants. DI couples were five times more likely than IVF couples to say that it was a joint responsibility to initiate and sustain the motivation to keep trying for a child. A staggering 18 out of twenty IVF respondents identified the woman partner unilaterally initiating and sustaining this responsibility, comparing to only ten DI respondents. Even those in the IVF group who had children between interviews did not change their perception of who was the treatment motivator. One man in the IVF group explained it this way.

> "It's got to be Jane's decision, because with IVF she's the major player. She's the one that's got to go through all the pain and discomfort... I don't have to. All I've got to do is the odd injection and drive her around a bit and hold her hand." *Bill*

When looking at DI and IVF in terms of gender involvement, DI differs from IVF in several obvious and important ways. DI is less invasive and time consuming per cycle. Being easier and posing fewer risks, people subsequently often have more DI cycles than with IVF. Of particular note, DI requires the couple to actively relinquish the genetic paternity of the male partner and involve a third party in the form of a sperm donor. Couples using DI are more likely to be equally involved in the decision-making process to initiate treatment, *because* they will have needed to address these issues before proceeding with DI, as with this couple.

> "It was a decision that we both made that we wanted to have children. And I wouldn't have gone through with it if I hadn't felt John was one hundred percent behind me and he is." *Naomi*

Table 4.2 below shows the gender motivation to initiate and continue treatment, based on parent status at the first interview.

Table 4.2 Gender motivation for treatment by parent status:

	Parents (n=21)	Childless (n=19)
Female	10	17
Joint	11	2
Male	0	0

Again, there is a marked difference in the perception of gender responsibility in infertility treatment decision-making, this time between those who are parents and those who are not. Just over half the parents in first interview (including the expectant DI couple) said they took on that responsibility jointly, compared to only one in ten of childless respondents. Thus it appears, that in addition to couples having DI, fathers are more likely to be involved in joint decision-making. This is contrary to one study with couples who had an IVF child, which did not find gender differences in decision-making (Daniluk, Pattinson, Zouves, & Mitchell, 1993). Becoming a parent is a significant life transition, pulling both men and women into discussing the choice and implications of trying to have more children, as with this DI father, concerned about affording more treatment.

> "Whether we will have another a child or whether we won't, whether we go for more treatments... We had a difficult year financially, when Olivia went into the programme. There's always means of getting more money... You either eat spaghetti and baked beans every night... instead of roasts." *Vladimir*

Initial treatment limits

What limits do people have when they first set out on infertility treatment? Once people embark on infertility treatment, different treatment options are often tried, starting with minimal invasiveness and tending to increase in complexity and cost (RESOLVE & Aronson, 1999:261). The treatment people choose to try depends on several factors, including the cause of infertility; the availability of treatment (and donors); resources available to pay for treatment; and what treatments are regarded as morally appropriate (Deveraux & Hammerman, 1998:48). There were several options to resolve infertility that participants would not have tried when their infertility was first diagnosed, showed below in Table 4.3.

Table 4.3 Limits at diagnosis:

	DI (n=20)	IVF (n=20)
None	10	13
DI	4	2
IVF	2	3
Adoption	4	2

The most fascinating result was that just over half the participants said that when infertility was diagnosed, there was *nothing* that they would have hesitated to try. They would have tried any type of treatment in their attempt to have children, like the woman below.

> "When you're in that situation, if they said 'stand upside down and do something', I was so desperate, I don't think there was anything in particular I wouldn't have done." *Glenys*

Interestingly, this group who identified having no limits were two thirds more likely to be *parents* already, suggesting that persistence is rewarded up to a point. Those with no limits are more likely to persist with treatment and are more vulnerable to experiencing difficulties in moving on from treatment, especially if they have not have the children they wanted.

> "Each time you get to a new level you think 'this is our saviour - this will fix it'. All the way along we just persevered." *Paul*

People's initial treatment limits were found at times to change. This shows that limits are personal, tempered by experience, and also influenced by the actual availability of various options (Frank, 1989:95). When male infertility was first diagnosed, one in five DI participants would have hesitated to use donor sperm. However, these same people went on to have several DI cycles. One DI couple hesitated about IVF upon diagnosis, but then went on to have IVF using donor sperm after unsuccessful DI cycles. DI was preferred to adoption as a way of resolving childlessness, while maintaining a genetic link with children (Daniels, 1994; Frank, 1990a; May, 1995). Seven participants would not have adopted children when infertility was first diagnosed, and none of these (mainly DI) respondents went on to adopt during the two and a half year study. Two women, who had children by donor sperm, would not have used donor eggs to help them conceive and another woman said:

> "I don't think I'd be happy with donor sperm, but I'd be happy with donor eggs, so that's crazy isn't it. It's illogical." *Naomi*

The Influence of values and religion

How much do values and religion influence people's choices with infertility treatment? Values give cause to hesitate, think carefully about and discuss treatments designed to assist fertility (Glazer & Cooper, 1988, Cooper & Glazer, 1994; Frank, 1990a; Haker, 1998; Lesch, 1998; May, 1995; Molock, 2000; Peoples & Ferguson, 1998; Vercollone et al., 1997). The impact of religious values on infertility choices should not be underestimated (Lee, 1996:95). These values have a bearing on what infertility treatments people feel comfortable with personally, as this woman found.

> "Manmade technologies were forcing us to pursue something that was not coming to us through natural means. And I personally felt that if it couldn't happen naturally by now with some intervention like AI, then we were going against nature and it might not be physical nature, but also in a spiritual sense that maybe we weren't meant to have children in this way." *Clare*

The participants in this study, drawn from fertility clinic patient lists, are not representative of all those facing infertility in terms of their values. From my professional experience, clinics rarely see individuals of strong, fundamental faith, who might experience intense moral conflict about having infertility treatment. These people are less visible and therefore more difficult to access in research. Religious directives questioning or forbidding the use of one's only means of achieving a pregnancy can create significant personal dilemmas. Several religions, developed for hundreds of years *before* the advent of organised assisted reproduction, are either cautious or actively sanction a number of central aspects of reproductive technologies (Molock, 2000:257). The Catholic Church states that instead of having infertility treatment, the suffering caused by infertility creates an opportunity for sharing 'the Lord's cross', and is a potential source of spiritual fruitfulness (Orr et al 1990:45). Subsequently, people wanting to use IVF may withdraw from the Catholic Church (Fryday, 1995:33). Several participants expressed anger toward the church's judgmental stand against reproductive technologies, when it was their only way of achieving a pregnancy.

> "These churches condemning IVF, making all these emotive statements on it - spiritually, it's turned me right away from religion. It really irates me when people are making statements that are taking away your right to having a child, whereas it is just another medical thing you're doing." *John*

In creating more embryos than can be used immediately, IVF directly juxtaposes personal values against science. The Christian view finds embryo freezing offensive, by "exposing the embryos to great risks of death or harm to their physical integrity and depriving them, at least temporarily, of maternal shelter and gestation" (Schenker, 1992:7). One IVF couple said their Catholic faith would prevent them from discarding excess embryos (Cooper, 1997).

> "We are both pro-life and with IVF we would have been okay, but we wouldn't be happy about throwing out any embryos. So if a number of embryos were fertilised, from my point of view they would all need to be used." *Stephen*

About three quarters of respondents said that their beliefs and values did *not* influence their choices with infertility treatment. Their comments included: "farmers use reproductive technologies" (this couple were farmers); they "use rational, common-sense and accept and act on the situation"; they "disregarded Roman Catholic background"; and they "have family support". Most of these people did not identify as having any particular religious beliefs, believing in fate and causal determination (Fischer, 1994:191), such as the woman below.

> "I don't have any particular religious beliefs. I call myself a bit of a fatalist. If it's going to happen, it will

> happen and if it doesn't, well it wasn't meant to be. And to that end, I can cope with it." *Lois*

However, about a quarter of participant's infertility treatment decisions were influenced by their religious beliefs and values. One Christian couple said that DI is "not natural", and initially hesitated about using this only means of having children. However, after gaining the support and blessing of their families and church minister, they extended their initial treatment limits and went on to have DI. If this support had not been forthcoming, then the couple would be faced with three options: firstly, withdrawing from these sources of familial and spiritual support; secondly, being private and hiding the truth; or thirdly, abandoning the possibility of pregnancy to follow the directives of church and family. Fortunately here, congruency between religious values, family support and reproductive choices was achieved. The woman faced clear direction not to get pregnant before marriage from her Christian mother, even in the light of known infertility,

> "because that's the way she's brought us up. And I couldn't help thinking I wonder if all the contraception that we did take was in vain! And maybe if we hadn't been so careful earlier on, we may have had something. But you just don't know." *Elizabeth*

However in another situation, the same consistency was not achieved and the second option of limited disclosure was employed. A man from a strict Catholic family background chose not to tell his parents about their grandson being the result of donor insemination, precisely *because* of the conflict he anticipated from his parents, and his fear of them rejecting the child. Therefore, while religious values had not limited the couple's treatment options, their donor son had been prevented from having knowledge of his genetic background and his grandparents prevented from knowing their grandson was not genetically related,

> "only because it's a religious debacle - it's like abortion. If you went and had six abortions, you wouldn't go and tell your Catholic Mum and Dad, who would be totally against anything like that." *Vladimir*

Continuing treatment

Deciding to start a particular treatment is but one stage in the decision-making sequence required of people faced with infertility. There are many more decisions involved during treatment. By the second interview, seven couples had stopped their infertility treatment. That left 13 couples who were either actively continuing treatment, in limbo or having a break. The influence of gender and parent status in sustaining the motivation to continue with treatment for these 26 people is contained in Table 4.4 below, and can be compared with tables 4.1 and 4.2.

Table 4.4 Continuing treatment by gender and parent status:

	DI Parents (n=7)	IVF Parents (n=3)	DI Childless (n=7)	IVF Childless (n=9)
Female	2	2	4	7
Joint	5	1	3	2
Male	0	0	0	0

The most striking outcome was that time had not altered the gender balance, and results were very similar to the first interview. Parents were again more likely to be jointly motivated (six out of 11) than childless participants (five out of 15). As raised earlier, parents are more likely to make decisions jointly, because fatherhood after infertility engages men actively and responsibly in the process of having children. In contrast, childless IVF participants (seven out of nine) saw the woman partner motivating further treatment, as explained by this childless woman:

> "I've been really pig-headed and stomped on and wanted to do it" *Maureen*

Why is it that childless people going through the IVF programme are much more likely to continue treatment driven by the woman's motivation? Similar to starting infertility treatment, the personal and social pressure for women to become mothers (Collins et al., 1992; Daniluk, 1988; Nachtigall et al., 1992; Stanton & Dunkel-Schetter, 1991) motivates women to assume responsibility with reproduction. IVF, in particular, has a direct and strong impact on women's bodies, requiring great commitment to continue. This includes many injections, side effects from medication, scans, blood tests, egg pick-up and embryo transfer (see Chapter One and Appendix 15 for more detail on IVF). Woman's decision-making power over infertility treatment was recognised by some men.

> "I wasn't very keen. I was quite happy to leave it as it was, but it wasn't up to me. She's the one who's got to go through all the hassles and mucking around and changing the body's rhythms and pain and the disappointment when it doesn't work... It's pretty easy for us... It's not easy on the woman, so you've got to try and support her through it." *Derek*

Factors limiting treatment

What factors constrained people from having further infertility treatment? This is of central interest to this thesis. These are the factors that people take into account when deciding to continue or discontinue treatment (Frank, 1990a:162). Some limits on people continuing treatment were commonly cited and others were not. Table 4.5 below summarises key treatment limits at the first interview, in order of their importance.

Table 4.5 Factors Limiting Treatment:

	DI (n=20)	IVF (n=20)
Emotional strain	6	14
Cost	11	7
Age	7	7
Number of cycles	4	4
Side effects & risks	0	5
Number of years	3	0

The most commonly identified limiting factor was the *emotional strain* of treatment (also found by Frank, 1990a and Goldfarb et al., 1997). Half of all participants at the first interview, and two thirds of those who had not stopped treatment by the second interview, cited emotional strain as a constraint. Predictably, those continuing with treatment more commonly identified emotional strain as a limit. People who have moved on from treatment are more likely to have distanced themselves from the intimate stresses associated with ongoing or incomplete treatment. In particular, twice as many childless people than parents and twice as many IVF participants than DI said that treatment stress constrained them. Ten out of twelve childless IVF respondents said that emotional strain was a limit on having further treatment. IVF is well established as being stressful (see Chapter One) and only one IVF couple in the study had children through treatment, so it is to be expected that IVF participants would experience more emotional strain. The greatest emotional strain was caused by failed treatment cycles and miscarriages, as this man said.

> "You must be very strong to be able to go through that emotional upheaval, because it is an upheaval. Time and time again and being rejected time and time again. How can you go on?" *Ian*

The *cost of treatment* was a limit for just under half of all participants in the first interview and just over half of those continuing in treatment in the second interview. At both times, DI respondents were more likely to see treatment cost as a constraint on the amount of treatment they could have, rather than their IVF counterparts. This is interesting, given that user-pays IVF is far more expensive than DI (see Appendix 15 on treatment costs), and given that IVF couples spent approximately $2,000 more on infertility related costs. Two of the DI couples, who found cost a constraint, moved onto IVF with donor sperm, one of these couples privately funding their IVF. As people tend to undergo more DI cycles than IVF, ongoing treatment expense is an issue. One DI mother put the cost factor this way.

> "You can't keep going and getting yourself into debt, you've got to be realistic. You've got to focus on things, because you're not going to fall in if you're stressed out about money worries." *Olivia*

People's *age* was identified as a limiting factor for one third of all participants at the first interview, increasing to just under half of those who were still in treatment or undecided by the second interview. While responses were initially evenly divided between DI and IVF, gender was significant. Age was a limiting factor for eleven out of twenty women, compared to only three men. Women are more likely than men to be conscious of their biological clock and the reproductive constraints of advancing age. However 18 months later amongst those who had not stopped treatment, any gender discrepancy had disappeared and almost three times as many DI, than IVF, respondents stated age was a treatment limit. IVF is probably perceived to have some control over advancing age, with the medication used and the possibility of donor egg. One IVF woman said that "age is only a limiting factor for doctors", and that she would keep going until she was 55 (Jan). Another woman said that

> "from being a teenager, you always think 'oh forty that's sort of the limit, because of the quoted figures about Downs Syndrome'... You would hope to have children by the time you were forty, and now every year that ticks by, every birthday is a reminder that you're that bit closer to forty." *Charlotte*

Related to age, three people spontaneously mentioned that their physical response to infertility treatment had declined over time, leading them to reassess how worthwhile it was continuing. One woman's health was a real consideration in having more treatment, which concerned her partner.

> "She can't walk sometimes and her hands play up and sometimes even her back... Ann's real fear is if her feet get so bad, that she won't be able to walk, that she'll be wheelchair bound. It's not a nice thought. Having a child - we wouldn't not love it or anything, but I'd have to give up work." *Ian*

The number of treatment cycles and the number of years spent in treatment were not seen as particularly important limits. Four out of five participants were not aware of personally having *any* limit on the number of cycles they had. This proportion even increased slightly for those continuing treatment by the second interview. It is surprising that the vast majority of participants did not perceive the number of years in treatment as an issue, given the ongoing and inconclusive nature of infertility and treatment. The goal of having children justifies the number of attempts and time spent trying, as this woman says

> "We had the same goal, so I don't think we ever really sat down and said 'well look we're going to go for 28 cycles'... Luckily with (our daughter) it happened within ten - which even though it is quite high, perhaps it

> would have been harder if it had been the other way round, like 16 the first time... But I think we wanted the same thing, so we just kept plugging!" *Joan*

There were just five men in the IVF group who said that *physical risks and side effects* acted as limits to further treatment for them (see Appendix 15 for treatment risks and side effects). Men often feel helpless to relieve IVF side effects on their partner, knowing that they too want to have a baby. Men are reported as ascribing more weight to the potential physical risks and side effects of infertility treatment, than women (Frank, 1990b:59), acknowledged here.

> "There's a toll to be had in terms of physical and psychological endurance. And the side effects aren't to be denied and they don't mean your hair turns green and you start walking up the wall, but there's a real pressure in those sort of treatments." *Nicholas*

However, for some people "limits were not an issue" (Valerie) and they "never put any limit on it" (Harry) as "the goal surpassed all else" (Samuel). Limits were seen as a brake on hope - that the desired outcome wasn't as important as it should be. While self-defined limits may foster a greater sense of control over their treatment destiny, limits on treatment represent limits on people's hope for a child. This woman did not have any treatment limits.

> "They'd suggest something and we saw a bit of light and took to it. Nothing really frightened me. People used to say to me 'how many treatments will you have?' and I'd say 'we don't know, we'll review it - I may have ten or twelve'." *Debbie*

The changing nature of treatment limits

Do people's initial infertility treatment limits change? As time passed and infertility treatments failed, most participants pushed back the limits they had on infertility treatment. Commonly, people extend their limits to consider treatments they initially never imagined trying, over more years than they anticipated (Daniluk, 2001a:125, 2001c:52). People can proceed almost automatically from one treatment type to another, moving upward on the medical treatment ladder or repeating the same treatment over and over (Diamond et al., 1999:162). They may not be ready to abandon their significant investment of energy, effort and cost, without a child. Simultaneously, reproductive treatment options continue to increase in range. One study found that ninety percent of women would resume infertility treatment, if a new treatment became available (Leiblum & Greenfeld, 1997:14). This woman agreed:

> "When... there's another treatment that's sort of coming on the market... it gives you a bit more hope - that will it be available for me... A bit more of a chance, once we've failed." *Valerie*

People commonly extend their initial limits by undertaking procedures that they had previously hesitated about, such as having tests they find embarrassing; injecting drugs that have unpleasant side effects and risks; undergoing treatments that are painful, invasive or have a low success rate; using donor gametes which bypass sought after genetic parenthood; and trying to conceive years after an original cut-off point. Only one person at the time of the second interview said that they had noticed no change in these limits, as they continued with treatment. The main limits that changed and *increased* over time were: emotional strain, age and the number of treatment cycles. One man said, that at the start of treatment,

> "it seems like you'll do anything to achieve that wanted pregnancy so badly, you'd keep on walking over hot coals endlessly... There's a limit to everybody's stamina on those things and we've heard of people who have gone for nine or ten cycles and frankly I think that's probably getting up to the extreme level of endurance... Well six was plenty." *Nicholas*

Most apparent were the increases in people's perception of their *emotional strain* over time. One woman said "I'm more anxious, as time is running out" (Olivia). Over one third of respondents in both interviews identified increased emotional strain, notably half of the IVF group. In contrast, only one in ten respondents noticed their emotional strain decreasing over time. These people were three times more likely to be in the DI group, most of whom had stopped treatment, after becoming parents. Increased emotional strain from IVF is to be expected, given the treatment is more invasive and stressful, and was less likely to be successful by the time participants stopped. As one woman explained,

> "we've put our lives on hold for a long time... All of our friends said 'how do you keep going? How do you put up with the stress and strain?' We said, 'because we must'." *Jade*

Closely behind strain, *age* limits increased for one third of all participants. Twice as many women than men pushed back their age limit for trying to conceive, over time. Women are more closely aware of their age as a reproductive limit to start with. As women remain without the children they want by the age they originally envisaged as a personal limit, they are often still prepared to keep trying, as this woman points out.

> "Probably when you're younger you'd say 'right I'll try till we're 35' and when you got to 35, it would be 37, and when you get to 37, it's forty. So when you're younger you put this age thing on it, but as you go through it you're not going to stop just because you've turned 37 or whatever, are you?" *Glenys*

The *number of cycles* participants were prepared to undertake also increased over time. One quarter of respondents, in particular half the DI parents (with an average of 19 cycles), said they had more treatment cycles than they initially anticipated. Thus, a tendency is found for people to continue if the treatment is less expensive, less invasive and less stressful. Specific treatments might be identified as 'the last one', but as time passes and people face a future without the desired child, these endpoints can get delayed. The number of cycles is extended particularly by success, but also by lack of success. If treatment was not successful, people usually continue for a higher number of cycles than originally planned, to reach their goal of pregnancy. If the treatment was successful, people would hope for another pregnancy by continuing treatment. This was so for six respondents, including this woman, who had thirty DI cycles and four donor miscarriages to have one child.

> "It just became automatic... You had a miscarriage, went back, tried again, had another miscarriage, tried again... I think the longer it takes, the more determined you are... You become so desperate in the end... I knew that it had to work and be successful at some stage. If I hadn't got pregnant, it might have been a different story, I might have given up earlier." *Anna*

Therefore, the main factors that limited participants having infertility treatment - emotional strain, cost, age and the number of cycles - were also the same factors that were more commonly extended (except cost, which remained the same). This was particularly so for those people who had not stopped treatment, a higher proportion of whom cited almost every factor as both a limit and an extendible limit. This is not surprising, as it is those people (who are either active, non active or in limbo about having more treatment) who will have these limits in their minds as they grapple with their future decisions. One woman, reaching her age limit, was just leaving a medical specialist who had been advising her to stop treatment, when she got conflicting advice:

> "His receptionist was saying 'don't give up darling. Have a whisky. We have lots of older ladies in here who get pregnant... Women over forty, forty-five have got pregnant - don't give up.' I was really beside myself paying the bill. Here was this duck, his mother-in-law, I should really have socked her in the eyeballs. She didn't know what had gone on behind closed doors." *Norma*

Treatment perseverance

Those who are childless are more at risk of not feeling ready to stop infertility treatment, making them likely to persevere. Persisting with treatment creates a relentless, inconclusive stress to be lived with. It is particularly difficult for the person who persists, but also for their partner if persistence is not a shared characteristic, their families and friends watching on, and for the professionals involved with their ongoing care. Participants were asked what they would say to someone who seemed very focused on having children, and who seemed unable to stop treatment. The comments made are valuable, as they come from those who "have been there too" (Valerie). In fact, four women said that they couldn't stop treatment themselves, including this woman: "I couldn't tell them to stop. I can't tell myself that!" (Charlotte). All answers to this open-ended question were spontaneous and reflect a compassionate, yet pragmatic, approach to those who persevere with treatment. One man said of his wife:

> "It became to Anna, without any criticism to her, a crusade - she was fanatical. And quite frankly, her fanaticism at times drove me crazy and... alienated me. There were times that I said to Anna 'well look, why don't I go and live in a motel down the road and you just get on with life'. Because that is how focused, for want of a better word, that Anna was." *Dillon*

Interestingly, just over half the participants (particularly IVF) warned those having a lot of treatment not to let infertility destroy their lives, by letting it become an obsession. Respondents encouraged valuing what life held already, and developing alternative interests. One in five, mainly childless men, said that there is more to life than having children.

> "There's more to life than just having children. Don't let it destroy your life. Whilst it's an overwhelming goal... you've got to manage your expectations and at the end of the day, there may not be a child there and you can enjoy your life without children." *Murray*

The next most common response swung in the other direction, encouraging people to *keep trying* with treatment to have a (or another) child. Over half the participants encouraged people to keep going if they were still positive about having further treatment and if medically it was a reasonable course to take. Predictably, more parents, but also more men supported ongoing treatment. Three quarters of fathers supported persisting, such as this DI father.

> "If you are going to put this in a book, you should put in there somewhere that they should just keep trying. I think they should explore every avenue and they should use a thing like we used." *Joe*

People who persevered with treatment needed to be strong to withstand the *strain* from ongoing treatment failure, for just under one third of participants (especially those who were childless). Presumably treatment strain is easier to bear if one has children. Managing the *cost* of treatment and being *realistic* about their chances of success were both noted by a quarter of respondents. Others said that treatment works for some (including a couple who had had 11 unsuccessful IVF cycles). The reality of *having to stop* treatment at some point was brought up by one third of participants, who would encourage the acceptance of a time limit in treatment. While there is no defined end point to treatment, it is generally accepted that people have to stop sometime.

> "You have got to call it quits at some point. You've got to be able to get on with life and you can't keep going forever. You've got to be realistic about it... It's like walking in a time warp if you don't - you're never going to get ahead. It causes... stresses in your relationship and you've got to come to grips with it" *Lois*

Stopping treatment

How do people stop infertility treatment, when the possibility of having a child still exists through assisted reproduction? The process of stopping infertility treatment is complex and emotionally fraught (Ryan, 1993:160), especially for the childless, as it requires a level of conscious acceptance of an unwelcome reality. For three quarters of respondents, the decision to move on from treatment was, or would be, a clearly *conscious* one. However, one IVF couple did not know and the remainder of participants (mainly DI) anticipated slipping into stopping treatment, or being prevented from continuing by external factors (such as lack of treatment availability or funding). People having DI may have felt more open to further treatment, because they had a higher number of cycles and were more likely finish treatment successfully. This DI father advised that:

> "They should keep going until such time as they could be comfortable about a decision to stop. Whether they could get there is another question." *Frank*

The number of participants who consciously stopped or anticipated stopping treatment (thirty out of forty) was less than those 37 who consciously started treatment, discussed at the beginning of this chapter. While both figures are high, the process of stopping treatment is considerably more complex and demanding than that of starting (Wischmann, 2002). Fewer people still, who were continuing with treatment at the second interview, thought it would be a conscious decision to stop. One quarter of respondents expected that a *medical limit* would decide for them in the end - they were all in the IVF group (also found by Callan, 1988). Thus, IVF participants who had not stopped treatment assumed less control over the decision to stop, like this woman.

> "The only way we'll stop is when we're told that 'no, it's not going to work'." *Valerie*

Influence of gender and parent status to stop treatment

Women were found to motivate infertility treatment decision-making if the couple was childless, while parents were more likely to make joint decisions to start and continue treatment (see Tables 4.1, 4.2 and 4.4). Did the decision to stop infertility treatment reflect the same pattern? Table 4.6 shows the influence of gender and parent status at the first interview.

Table 4.6 Stopping treatment by gender and parent status:

	DI Parents (n=10)	IVF Parents (n=7)	DI Childless (n=10)	IVF Childless (n=13)
Joint	6	6	2	4
Female	3	1	4	7
Male	1	0	4	2

Once more, results neatly broke down, depending on whether the couple had children or not. Three quarters of parents said that it was or would be a *joint* decision to stop treatment. In contrast, only one quarter of childless couples said it was or would be joint decision. Half of the childless group in the first interview, increasing to two thirds of those who had not stopped treatment in the second interview said that it was, or would be, the *woman's* decision. Therefore, while women's momentum to start and continue with treatment was recognised by almost three quarters of respondents, this dropped to under half for stopping treatment. No men were seen to be responsible for starting infertility treatment, but one fifth identified men as responsible for deciding to 'move on'. Those twelve people who identified starting and continuing as a joint responsibility, increased to 18 when it came to deciding to stop. So there is a gradual shift to more equal gender responsibility in deciding to stop treatment. This man wanted to stop before his partner.

> "I thought we would've stopped long before we did. I have queried how long can you keep going for? How long can you cling to something that possibly is not

> there? I was so annoyed about continuing. Where was it going to end? Really it was up to Sophie as to when she decided enough was enough." *Martin*

Reasons for stopping treatment

Why do people stop infertility treatment? More than half the participants said that when they *had children*, they would stop. Not surprisingly, three quarters already were parents or pregnant. This backs up two studies which found IVF parents more likely to stop treatment (Callan et al., 1988; Daniluk et al., 1993). Those parents who did not think that being a parent would make it easier to stop treatment were not joint, genetic parents. They included one couple who parented the woman's child from a previous relationship, but had no children together; one IVF woman who had adopted out her child before being unable to have any other children; an adoptive mother; and the mother of a donor child. This man found stopping treatment easier after adopting two children.

> "It's infinitely easier, when you've got a wee toe-rag who's... still at home - who's still going to race around and cause you chaos and havoc." *Nicholas*

This result changed with those 26 participants who had not stopped treatment at the second interview - most men (all DI men and two thirds of IVF men) anticipated being *ready to stop without a child*, like this man.

> "I'd put children before financial stability any day... I'd like a family too, <u>but</u> I could also live without one... I ... challenge her to knock it on the head and finish IVF. But... it gets her back up and she says she's not ready, which is fine." *John*

In contrast, fewer than half the unfinished women anticipated feeling ready to stop treatment if they had not been successful. More than half the childless women who had not stopped treatment expressed worry about their future *if* they did not have children. One third of women unfinished with treatment (and a greater proportion of childless women) spoke of about not being able to imagine feeling ready to stop treatment.

> "Month after month when nothing happens and you can't see any end to it and you're not sure what will happen or how it will end up... You're not sure whether you will ever come to the decision to give up." *Mavis*

Half of all respondents, especially women, thought that *increasing age* and reaching menopause would stop them having more infertility treatment. Age and menopause may sound like an obvious brake to treatment, but donor egg programmes (not available locally when the research was initiated) now allow for the postponing of women's biological clock. For an unexplained reason, age was three times more of a limiting factor for DI participants, than those in the IVF group. Basically, people anticipate stopping treatment when they are either successful or when physically it is not possible to continue - suggesting that would like to continue until either they have children or cannot biologically have children.

> "Keep going, until either you feel you're too old or you've just had it." *Mavis*

The *partner's* decision to stop treatment was important for almost half the participants, mainly men like Dave: "I always believe if she says 'stop', stop's the word". Men were three times more likely to listen to their partners if they said they wanted to stop, than the other way around, especially if they were in active treatment, in limbo or having IVF. Partner's beliefs were also found to be influential on decision-making by Frank (1990b). This man said to his partner,

> "If you were saying 'no' and I was keen... I wouldn't have any say. You're putting your body through it and you're the one that keeps coming back and saying 'I want another go'." *John*

However, a number of women spoke of *not* being able to voluntarily leave infertility treatment, without having a child, such as this woman.

> "I'm still wanting to go and go and go. And it will always be in the back of my mind that, yes I do want to try and still push myself a bit more. They'll probably literally have to stop me, because I think I'd still want to try and I suppose it will be Murray that will turn around and... take me away from it." *Valerie*

Fewer than half the participants would rely on *medical recommendation* and information about their chances of success to help them make up their minds about stopping. This was particularly so for childless IVF respondents, three quarters of whom relied on medical recommendation and information (consistent with Callan et al., 1988; and Lalos, 1999). This man valued receiving medical feedback about their chances.

> "One slight turning point might have been the specialist telling us to think about giving up, being told your chances are almost zero - that it is not worth doing IVF. It is difficult, but they might have taken away that hope, which is that you've got no option but maybe just accept it a little bit." *Stephen*

The most commonly given anticipated reasons for stopping from those continuing treatment were lack of money; medical recommendation (particularly childless IVF respondents); and when they had children (mainly parents) by about half of the continuing participants. Surprisingly, given the stressful and often unsuccessful nature of infertility treatment, emotional strain was barely mentioned as stopping further treatment, despite it being a significant limit earlier on and despite being recognised in the literature (Braverman, 1997). This woman summed up her likely reasons for stopping treatment:

> "Once you've got a fair count of (treatment cycles)... over a period of time, you come to the decision... to accept the fact that this is really rather useless and fruitless... and money down the drain... Age is quite important - so obviously the older you get, the less likely you're going to be wanting to keep going." *Jane*

Spontaneously, just under half of those who had not stopped treatment, said that they needed *no information* at all to make their decision to stop. The decision to stop infertility treatment was seen as a personal one, particularly by parents (including adoptive parents), who saw their persistence rewarded by success. This backs up another study in which half the 400 respondents wanted to decide alone, or mostly alone, when to stop infertility treatment (Stewart et al., 2001). From the whole group of participants, including those who have stopped treatment, there is greater tendency to an internally perceived locus of control over the decision to stop treatment, rather than an external one, as this man notes.

> "Follow your heart. Keep going until you couldn't go anymore... Some of us may never stop, some of us may never accept the end. Some may accept it more readily than others. So give it your best shot. You will

> know in your own mind, and your own soul, when the time is there to stop." *Samuel*

When asked what they anticipated feeling after finally stopping infertility treatment, more than half the unfinished participants (especially childless and IVF respondents) said that they wanted to get on with other things in their lives; experience freedom from uncertainty; and needed to accept their situation. The other anticipated aspects of stopping were the ability to plan one's life more effectively (by one third, mainly IVF respondents); maintaining a high level of emotional strain (by one quarter, especially childless women); and concern about one's personal future (by one quarter, again particularly childless women). While the actual numbers are small, patterns are emerging about stopping infertility treatment being harder for women and those who are childless.

> "I just have to accept the fact that I can't have children. I am trying to accept the fact that I can't have children... Sometimes it's hard, sometimes it's easier... I just have to try and get on with it - with my life." *Ann*

How infertility decisions were made

Every person has a decision-making style and this flows over into infertility decisions. However, because the personal desire for a child is so emotional and powerful, people may make decisions differently to other decisions in their lives. In identifying how people made decisions about infertility treatment, some people clearly used similar processes to those they used in making decisions in other areas of their lives, but others had unique ways of decision-making in the infertility arena. Some respondents stuck to a plan, some were vague with their treatment intentions and yet others were immobilised about how to enact their treatment intentions. The general impression gained was that most participants found it hard to articulate how they made decisions (Bartlett, 1994:97) and took their decision-making processes about infertility treatment for granted.

> "Isn't that the same with everything? If you're going to buy a car, you go out there and you see what the options are and you talk about it. 'Well do we need an eight-seater or do we need a two seater? Is it red or white? Do we borrow the money?' You rationalise all

> those decisions and you come to the decision 'well, we think this is the best'. Not that having IVF is like buying a car." *Frank*

Just over one third of respondents spontaneously stated that their decision-making process followed a fairly easy and logical progression, an 'evolutionary' process (Greenfeld, 1997:43), where goals are set and limits are clear (RESOLVE & Aronson, 1999:261). Overwhelmingly, these people tended to be male and parents - in fact, ten out of twelve fathers said the process of working out how to try and have children was straightforward and created no problems. As Lee (1996:70) says, "men make decisions with their heads, always rationalising", typified by this man.

> "Like anything in life, you give it a bit of whack, and if it doesn't work well you've got to review it then. A lot of the steps over the whole thing, as long as the goal is the same, become a fairly natural progression and just naturally just crops up in decisions you make." *Peter*

About half of the mothers agreed, while the only childless person to describe the decision-making process in these terms was the man who had been through treatment for cancer. Maybe the process seems easier in retrospect for those who are parents and who have stopped treatment, with the memory of that painful era, with its ongoing dilemmas and uncertainties, receding over time. Another man spoke of making IVF and adoption decisions in business terms.

> "We knew we wanted another child and we did a marketing exercise to put our message across and it paid dividends." *Arthur*

In contrast, several people said that they unsure what the key components of making decisions about infertility treatment were. These people predictably had not stopped treatment, and were mainly in limbo about having more treatment or not. Living in a current drawn-out reality of facing dilemmas and making decisions about the important matter of having children is quite different to thinking back on that process, as this man reflects.

> "It's quite a complex decision-making process, because nothing's guaranteed and there's all kinds of variables and it's not a yes-no kind of thing." *Jim*

The most common spontaneously expressed key component of making decisions about fertility treatment was *couple communication*. Just under two thirds of respondents said that as a couple they needed to talk through what they were doing and where they were headed with their treatment. This was evenly divided between men and women, parents and childless and DI and IVF respondents, but was expressed more frequently by those who had not completed their treatment, than by those who had. Communication is critical for making satisfying couple decisions (Hollerbach, 1980:166). The essence is to talk about issues and feelings thoroughly over time, in order to reach a mutually acceptable agreement about the next concrete step, within a general plan (Daniluk, 2001c).

> "I think communication is the key. The times that have been really worse are the times that we haven't spoken properly to each other, talking about the one thing that we were both thinking about." *Charlotte*

Comments that participants made about how to discuss infertility treatment issues, with a view to making decisions, included:

- discuss the issues in great depth
- be very honest about how you feel
- listen carefully to each other
- try and understand each other's perspective
- pay attention to both facts and feelings
- talk through different scenarios, and their pros and cons
- debate new information
- re-discuss the issues after a lapse of time
- make a suitable time to talk about it
- don't take stress out on each other
- try to come to a joint, consensual decision

The literature has a number of suggestions to assist decision-making (Freeman & DeWolf, 1989; Hermansson, 1992; Manthei, 1990). A *decision tree* can help clarify the decision-making process regarding fertility treatment (RESOLVE & Aronson, 1999). This may include: choosing one particular treatment over another, continuing with treatment or taking a break, with their various pros and cons, risks and benefits. Such a decision tree or plan covers long-range treatment goals, to help take control and develop self-esteem (Davis & Dearman, 1991). A *coping budget* can weigh up whether to proceed with a particular treatment, or not (Furse, 1997:117), considering treatment-related costs in money, time, stress, pressure, anxiety, energy, health and relationship closeness. The pros and cons of each contemplated treatment can be identified and each treatment ranked in preference, then lists compared and discussed (Salzer, 1991). This couple used a similar process.

> "We talk about it, ad nauseam... We drew up sheets of paper with pros and cons - we didn't get very far with that. It was very much that weighing up one side versus the other... Apart from the logical stuff, there's also the emotional stuff that is hard to put in the pros and cons column because the weighting is different to that... We were both really careful about looking to each other and listening to try and pick out if it was more of an issue for one or the other of us." *Rose*

Some participants recommended gathering information to become an informed consumer of infertility treatments (Daniluk, 2001c:57). Infertility patients have been reported as lacking the necessary information to make meaningful decisions (Stewart et al., 2001). It needs to be recognised that people may not be able to understand or remember information presented about medical options (Chapman, Elstein, & Hughes, 1995:231), due to anxiety, and how complex information is presented (Hammarberg et al., 2001:381). Information gathered by 'scanning' (Janis & Mann, 1977:36) gets 'personalised' with people's feelings, desires and values (Frank, 1990a:163; Smedes, 1991:31). People gauge their chances of pregnancy through this 'personal filter' (Reading, 1989). New information can be consciously used in decision-making, as this man explains.

> "Every time we got some new information after having seen someone, we'd sort of debate it for days." *Jim*

Discussing a plan before, rather than waiting until during or after treatment helps avoid misunderstanding and conflict. Rather than agreeing on an infertility treatment plan that lasts a lifetime, people can find it helpful to make 'a plan for now' (Zoldbrod & Covington, 2000:337), in which they agree to re-evaluate later, either at a set date or as situations develop. The decision to stop treatment can also be made within a 'tentative' time frame (Daniluk, 2001c:77), allowing flexibility and extra time as required. This avoids creating fear as a rigid cut-off time approaches without a child. Time to 'sit' with a decision is seen to be helpful, in terms of assessing its fit with one's life (Ryan, 1993). Thus, cumulative or incremental decisions can emerge over time with 'adaptive flexibility' (Janis & Mann, 1977). This man also recognised that plans, limits and situations change over time.

> "You've got to talk to everyone available that you would respect and get an idea of the direction that you need to go in, but then you need to come back and jointly rationalise it on a step by step basis. So if you were to ask at the outset 'what is your plan for treatment?', we wouldn't have been able to tell you. We would have just said 'oh well, we'll give it a go, see if it works or not'. It's very hard to plan." *Frank*

A balance between logical and emotional decision-making is called for (Daniluk, 2001c:76; Peoples & Ferguson, 1998:155). The logical or rational aspect of infertility decisions would include weighing up finances; physical side effects; chances of success; career choices; and relationship and social needs - how much more treatment to go through and when. The emotional or intuitive aspect of infertility decisions is more difficult to ascertain, as it involves 'intangibles' (Janis & Mann, 1977:24), such as hopes and dreams; self concept; family and social expectations; stress and coping; and spiritual faith and values about what is important in life. However, these non-rational aspects are reported to be very influential in people's decision-making (Hechter & Kanazawa, 1997; Loomes & Sugden, 1982; Rapoport, 1989; Tversky & Kahneman, 1981). Decision-making requires finding a balance between these different aspects. One couple found a clear gender balance between passion and pragmatism in infertility decision-making.

> "Mary-Ann is a bit more passionate in her thinking and I'm very pragmatic... We came from a reasonably good understanding and it was a good balance, a really good balance." *Bob*

Couples can experience major differences with each other in making decisions. Partners frequently are *not* simultaneous in their preferences

(Bombardieri, 1993:382). Effective decision-making requires effective communication, in checking out the reality for each partner. A lack of agreement about a 'second choice', can cause impasse and increase isolation within the relationship and also socially (Cooper & Glazer, 1994:123). This can lead to the more ambivalent partner submitting to the stronger feelings of the partner, or to postponement of decisions (Bombardieri, 1981), as this couple in limbo found.

> "It's not going to happen in a weekend. It's got to be talked about, but not a rash decision after a couple of day's talking. It's probably going to need help from others, but in the first instance we need to sit down and be totally honest with each other." *Charlotte*

Conclusion

This chapter is the central results chapter containing details from the three interviews over the two and a half year duration of the study. Infertility treatment decisions are among the most important, challenging and taxing decisions in life for someone experiencing infertility. Which infertility treatment path is right for an individual or couple was found to be highly personal. Choices were influenced by treatment prognosis; gender; age and stage in life; financial position; parental status; family composition; emotional strain; spiritual values; and personal need. These decisions have direct life-long implications for whether people have children or not, and whether these children are fully genetic or the result of donor gametes or adoption. The next chapter focuses on what role professional counselling had for participants in making multiple decisions about infertility treatment.

CHAPTER 5

Infertility Treatment Decisions: The Role of Counselling

The counselling role in infertility treatment decision-making is a professional adjunct to the main body of the thesis. Infertility counselling is a specialty counselling area associated with the provision of medical treatment for infertility, which has become increasingly important as assisted reproduction has rapidly developed (Jennings & Lee, 1995:13). Today's world of increasingly complex assisted reproduction calls for increasingly complicated infertility treatment decisions (Greenfeld, 1997:45). Infertility counsellors are in a unique position to assist people with the multitude of decisions concerning infertility treatment (Jennings, 1995:5) from the point of diagnosis, until some sort of resolution is reached in the quest for a child.

Counselling roles

Historically, infertility counselling developed through the adoption field (Covington, 1988:23), with little attention being paid to the particular psychological needs of those experiencing infertility. Since the 1980's, the field of infertility counselling has grown dramatically in terms of the numbers of professionals working in the area; its inclusion in or affiliation to infertility clinics around the world; the amount of research, publications and professional development being undertaken (Burns & Covington, 2000:21); and the active emergence of professional infertility counselling associations.

According to Reproductive Technology Accreditation Committee (RTAC) regulations put out by The Fertility Society of Australia, which New Zealand clinics abide by, counselling is now recognised as a significant component of infertility treatment, and must be available through any approved fertility clinic (RTAC, 1988). Although all members of the fertility team 'counsel and console' clients (Burns & Covington, 2000:475), the infertility counsellor is a qualified social worker or psychologist (Boivin, 2002c; Corrigan, Daniels, & Thorn, 2002), and at times psychiatrist, or a marriage or family therapist. Infertility counsellors are the mental health professionals who provide specialist services in the form of psychological assessment, psychotherapeutic intervention, emotional-educational support, psychosocial research and staff consultation.

Infertility counselling aims to "explore, understand and resolve issues arising from infertility and infertility treatment and to clarify ways of dealing with the problem more effectively" (Strauss & Boivin, 2002:4). The provision of counselling services is increasingly viewed as an essential component of infertility treatment (Applegarth, 2000; Appleton, 1990; Atwood & Dobkin, 1992; Batterman, 1985; Bitzer, 2002; Blyth, 1990,; Blyth & Hunt, 1995; Boivin, 2002a, 2002c; Boivin et al., 2001; Born, 1989; Bresnick & Taymor, 1979; Burns & Covington, 2000; Connolly et al., 1993; Cook, 1987; Cooke, 1998b; Cooper & Glazer, 1994; Corrigan et al., 2002; Covington, 1988; Craig, 1990; Crawshaw, 1995; Daniels, 1986, 1992, 1993, 2002; Daniels & Stjerna, 1993; Daniluk, 1991; Daniluk, Leader, & Taylor, 1987; Deveraux & Hammerman, 1998; Diamond et al., 1999; Ellis, 1982; Epstein & Rosenberg, 1997; Frank, 1984; Furse, 1997; Greenfeld, 1997, 2000; Greenfeld, Mazure, Haseltine, & DeCherney, 1984; Greenfeld, Diamond, Breslin, & DeCherney, 1987; Greil, Leitko, & Porter, 1988; Hafkin & Covington, 2000; Hunt, 1989; Kainz, 2001; Kententich, 2002; Klock, 2000; Klock & Maier, 1991a; Lee, 1996; Levin, 1993b; Lesch, 1998; McWhinnie, 1995; Menning, 1979; Molock, 2000; Monach, 1993, 1994; Naish, 1994; Needleman, 1987; Newton, 2000; Newton et al., 1992; Oke, 1999; Pengally, 1995; Reading & Kerin, 1989; Rosenfeld & Mitchell, 1979; Rosenthal, 1992; Salzer, 2000; Sewall, 2000; Shapiro, 1982, 1988, 2000; Shaw, Johnston, & Shaw, 1988; Silman, 1995; Stanton & Burns, 2000; Strauss & Boivin, 2002; Terzioglu, 2001; Thorpe, 1994b; Warnock, 1985; Zoldbrod & Covington, 2000).

The danger in medically treating infertility is that the emotional impact of infertility is neglected and the problem reduced to solely a biological or medical one (Kententich, 2002:1). The Warnock Report, an early British landmark on international debate in the area of assisted human reproduction, specifies that counselling should be available for all involved with infertility treatment, with the aim to help individuals understand their situation and make their own decisions about what steps should be taken next (1985:3.4). The basic aim of infertility counselling is that people understand the implications of their treatment choice, receive adequate emotional support and cope in a healthy way with the consequences of the infertility experience (Boivin, 2002c:51).

There are four main areas of infertility counselling (Australia New Zealand Infertility Counsellors Association (ANZICA), 1995; Australian National Bioethics Consultative Committee, 1990; Kings Fund Centre, 1991; RTAC Committee, 1988). These are information giving counselling; implications and decision-making counselling; support counselling; and therapeutic counselling. ANZICA also includes crisis counselling, counselling for non-genetic parenting and stress management counselling. In practice, these tasks normally overlap (Strauss & Boivin, 2002:4). As the primary focus of this thesis is on infertility decision-making, the decision-making component of implications counselling will be highlighted in this chapter.

Implications counselling is said to focus on the mutuality of the decision to seek treatment and the range of options to deal with childlessness, including the childfree option (Blyth & Hunt, 1995:59). The goal of infertility counselling is to enable those concerned to understand the implications of a proposed course of action for themselves, for their family or for any children born as a result (ANZICA, 1995:17). Implications counselling is regarded as necessary for achieving *informed consent* (Atkin & Reid, 1984:66) and therefore must be available to all who access infertility treatment (British Human Fertilisation and Embryology Authority, cited in ANZICA, 1995:17). However, referral to counselling services can be an issue, as this woman found.

> "My Gynaecologist never offered. I cried in his surgery and he just put his head down and kept on writing. So obviously I did need help of some sort and I think he should have advised me." Glenys

Decision-making counselling

One of the most difficult challenges of infertility is the multitude of constant decisions that need to be addressed from the moment fertility is questioned, until some resolution is reached (Shapiro, 1988:109). Those in the midst of the infertility crisis and overwhelmed by the implications of the choices they must make within a pressured time frame, can feel an intense and urgent need to make decisions. The process is often such a long, complicated and emotionally charged one, that decision-making is an evolving process. The counsellor is a key professional to spend the time to develop a trusting relationship with people facing infertility, working through the meaning and implications of people's choices as a couple and as a future family, and essentially helping people to make their own decisions (Appleton, 1990:844).

Infertility counselling should provide the opportunity to come to an informed and considered decision regarding future options (Blyth & Hunt, 1995; Kings Fund Centre, 1991; Reading, 1989) and their viability and timing (Daniluk, 2001a). Helping those experiencing infertility to evaluate treatment options, including family-building alternatives such as the use of donor gametes, adoption and childfree living, is part of the counsellor role (Batterman, 1985; Bitzer, 2002; Burns & Covington, 2000; Cook, 1987; McWhinnie, 1995; Needleman, 1987; Read, 1995; Reading & Kerin, 1989; Rosenthal, 1992; Strauss & Boivin, 2002; Thorpe, 1994b; Wischmann, 2002). Cultural and religious factors also require respect from infertility counsellors (Gordon & Barrow, 2000:510) as they influence the experience of infertility and treatment decisions (Molock, 2000:263), and the shaping of medical treatment plans and counselling goals (Sewall, 2000:421).

The use of donor gametes (sperm, eggs and embryos) is of special significance in implications counselling (Reading & Kerin, 1989; Snowden & Snowden, 1997). Counselling tasks at this time are to ensure a thorough understanding of the issues involved with donor gametes; explore the loss of a 'genetically-shared pregnancy' and child (Zoldbrod & Covington, 2000:336); reach agreement on informing donor children of their origins

(ANZICA, 1995:8); and deciding on a treatment plan. These decisions are the clients' decisions to make, and they include when, where and how they will proceed with the use of donated gametes to build their family, within current legal, ethical and medical parameters. Participants in the study generally identified the same primary areas and stages of decision-making counselling found in the literature.

Contact with counsellors

Receiving constructive feedback about how clients experience counselling and what they would like from counsellors can be problematic. As discussed in Chapter Two, I was conscious that my double role as researcher and (fairly new) IVF counsellor may cause ambivalence to some participants about revealing their experiences with counsellors. I was concerned that some people may fear their future treatment with the clinic could be negatively effected. However, respondents were refreshingly direct and honest about their infertility counselling experiences.

> "It doesn't mean you're going to have a baby, but I think it helps." *Colin*

At the time of the first interview, 13 out of the twenty respondent couples had attended only the one compulsory session prior to treatment, while four couples had two or three sessions together with the clinic counsellors. A few participants had more than ten counselling sessions. Two of the men had not attended the initial counselling session, despite it being mandatory prior to treatment. Neither of these men wanted to see a counsellor. Men have been reported as being less likely to seek counselling to help cope with their infertility (Lee, 1996:47). One man said:

> "I've never believed in counselling and if you've got problems... you deal with it through the families or churches... I don't believe in the counselling aspect of the whole system, not for me personally. Not that I believe I ever need it. I get enough counselling through Olivia!" *Vladimir*

Another man attended counselling to help with severe relationship stresses, caused by having two children with another woman.

> "I didn't want to do any counselling. I didn't want to go along and talk to someone about my relationship. I went for our relationship - really, it was like a last ditch thing." *Tama*

Noticeably more DI women went to see a clinic counsellor for infertility issues on their own, than did men and IVF women. Only one man out of the twenty interviewed had ever seen a clinic counsellor individually. Women both self-referred for infertility counselling and were referred to specialist services. Three participants defined sessions with their minister and doctor as counselling. Because of the more direct impact of treatment on women and that women more readily identify the emotional stresses of infertility, they are likely to be greater users of fertility counselling services, often to assist with emotional healing. This woman said that counselling had helped her

> "look at the more positive things about myself, apart from the fertility issues... rather than being really negative, because my body won't work for me." *Jade*

However, not all women wanted counselling and this woman thought counsellors spoke "a lot of bull".

> "Counsellor? I didn't know what the word was, and I don't understand it... For some people, it may be helpful, but for me, I don't need a counsellor. I solve my own problems and if I can't? Well, that's bad luck." *Jan*

In the year between the first and second interviews, most participants had no contact with counsellors. Interestingly of those that did, all were childless, except one woman. One DI couple saw the DI counsellor once, the woman saw both her and a specialist Anxiety Disorder team many times. In contrast, one third of IVF respondents saw a variety of counsellors between study interviews for a variety of reasons. This included specialist psychiatric support; eating disorder support; independent counselling; and pre-adoption counselling. Three participants also saw me in my role as IVF counsellor. Three people subsequently saw me in my role as IVF counsellor, one of whom said that the research contact did positively influence her to seek further counselling.

> "I thought you were a very friendly, open sort of person and if I had of had you as a counsellor in the beginning, I might have felt more at ease." *Ann*

Counsellor role

Women, in particular, stated that they were clear about the role of the infertility counsellor. The key times for counselling, identified by at least three quarters of participants, were coping with treatment failure, information-giving, and support. At least half the respondents thought that coping during treatment; dealing with depression; coping with infertility strain; dealing with relationship issues; and coping with pregnancy loss or stillbirth were also key times to access counselling services. Gender differences were revealed, when more men than women, identified *information-giving* as part of the infertility counselling role. Information-giving increases the likelihood of wise decision-making (Gordon & Barrow, 2000:505). Focusing on information in counselling may feel safer and more comfortable for men, who are used to being private and distancing their emotions (Deveraux & Hammerman, 1998; Lee, 1996; Mahlstedt, 1985; Stanton & Dunkel-Schetter, 1991; Wright et al., 1991; Zoldbrod, 1993). This man appreciated getting information.

> "We made headway in this infertility problem... from the time that we had professional help and... that helped us make decisions and the fact that we had a bit of counselling... You gather a wealth of knowledge and understanding and I think it really does subconsciously help you make decisions, and decisions become easier." *Arthur*

Women emphasised getting help to *cope* with infertility treatment, pregnancy loss and anxiety more frequently than did men, a pattern replicated in other studies (Abbey et al., 1991a; Appleton, 1990; Blyth & Hunt, 1995; Bresnick & Taymor, 1979; Burns & Covington, 2000; Collins et al., 1992; Connolly et al., 1993; Crawshaw, 1995; Daniels, 1989; Daniluk, 1988; Deveraux & Hammerman, 1998; Greil, 1991; Lalos et al., 1986; Leiblum et al., 1987; Newton et al., 1990, 1992; Seibel & Levin, 1987; Shapiro, 1988; Slade et al., 1997; Wischmann et al., 2001; Wright et al., 1989, 1991; Zoldbrod, 1993). This woman had sought a lot of counselling support with her infertility.

> "My depression was a really dramatic way of showing how I was coping with it and how important and how central it is to me... Until there's that finality, there is still hope and that step is going to be hard coping with... But there is also the limbo and that is also hard on us. We don't know where we're going." *Charlotte*

Participants were asked about the infertility counselling role regarding decision-making, evaluating options for the future and moving on. Out of the 38 respondents who attended clinic counselling, half thought *decision-making* should be part of the counsellor's role (as do Appleton, 1990; Daniluk, 2001b; Deveraux & Hammerman, 1998; Hermansson, 1992; Reading, 1989; Sewall, 2000; Shapiro, 1988). Twice as many women than men and more DI participants than IVF emphasized this. Three quarters of respondents, particularly parents, thought that counselling should address people's *future options* (see Carter & Carter, 1989; Daniluk, 1991; Diamond et al., 1999; Sewall, 2000). Again, three quarters of participants said that counselling should address *moving on* from treatment (see also Appleton, 1990; Australian National Bioethics Consultative Committee, 1990; Blyth & Hunt, 1995; Gordon & Barrow, 2000; Kings Fund Centre, 1991; Schmidt, 1998a). Similar proportions would have liked their own counselling to have covered decision-making, future options and moving on from treatment.

Experiences of decision-making counselling

What participants found helpful from their counselling was significantly less than what they identified the infertility counsellor as providing. Only half of those who thought decision-making was part of the counsellor role actually personally found it helpful; one third marked future options; and only one quarter of those identified moving on from treatment (similar to Hammarberg et al., 2001:378). Only three people out of 38 said counselling had addressed what treatments were available for them and five people about when to start infertility treatment. Particularly few IVF respondents found counselling helpful in addressing the issues involved in decision-making and moving on from treatment. Interestingly, most respondents who thought infertility counselling should cover the complex and demanding process of stopping treatment, did not in fact access counsellors for themselves at this time.

> "We didn't find (the counselling) really aided us a lot in our decision-making, because we had already got there. Down the track, if we were still struggling having not been successful, we probably might have made a bit more use of it then, so it's no reflection on (the counsellor). The fact that we didn't find it particularly useful is more that we were already geared up." *Rose*

It was surprising that two thirds of respondents did not find counselling had an influence on their fertility treatment path. In fact, no IVF respondent said counselling had any input into his or her treatment path. One quarter of DI participants found their counselling had a motivating or consolidating influence on their thoughts about treatment, dispelling fears. Disturbingly, one couple had a very difficult experience with a counsellor who "created more dilemmas" (Dillon and Anna), suggesting that they should not have treatment as their marriage wouldn't survive. Another man misunderstood the decision-making component of the counselling role.

> "There's no-one that you go to who can tell you what are the right decisions. The last thing you want to do is go to a counsellor who might tell you 'no, don't get inseminated for the next two months... You're not financially secure enough. You've got rates to pay, you're behind two weeks in your mortgage, so don't spend the money on insemination this month.' Is that the right decision? My love says 'it could be this month'. Who's to tell you that it's not?" *Vladimir*

Thus, an interesting picture is emerging about the role of decision-making infertility counselling. Up to three quarters of participants thought counselling would cover decision-making, options for the future, and moving on (and wanted it to), but only one quarter of respondents found it actually addressed the various decisions involved in continuing or stopping infertility treatment. Half of those who did not find counselling helpful with their infertility decisions said they already knew how they wanted to proceed with treatment, despite a sizable number of people being in limbo (as discussed in Chapters Two and Three). Three other people said that decision-making was not the reason they had counselling.

Why do people not find counselling helpful in terms of their infertility decisions? There are several reasons reported for not finding counselling as useful and helpful as they might (Cooke, 1998b; Thorpe, 1994b). Because few people have had counselling prior to entering an infertility programme, many may feel awkward about initiating contact with a counsellor (Boivin, Scanlan, & Walker, 1999:1385) and most are not clear about how to best utilise a counsellor, as this man said.

> "Having no experience with psychologists or psychiatrists in the past, I don't know what the end result was going to be. I don't know what they were working to. I don't know what we expected." *Martin*

It should be noted that most respondents had just one introductory counselling session. Thus, what was perceived as helpful will necessarily be limited to what can be realistically covered in one hour, on top of engaging the clients and giving information about the forthcoming treatment and related topics. It is not always possible or appropriate to cover issues like stopping treatment (as five people commented). At this early stage, people anticipate having treatment, and are hopeful of success. My professional experience showed that most people self-select out of counselling if they are doubtful about proceeding with treatment. An interesting contradiction emerged with most participants choosing not to have further counselling, yet overwhelmingly supporting mandatory counselling prior to entering a fertility programme and overwhelmingly suggesting that follow-up counselling be offered after a certain period on a treatment programme

In addition, by the time people get to see a counsellor, it may be years after a diagnosis of infertility is made (Blyth & Hunt, 1995:43), and people have often already made decisions about what treatment path to take, privately or in consultation with their doctor. Unless people are limited by outside constraints on their treatment paths, such as finances or age, or they are in a state of limbo about their treatment destiny, it is up to the individuals concerned to reach some inner and dynamic readiness to move in a particular direction (Monach, 1993:80,195). Many respondents expected to make decisions and solve problems themselves, without counsellor input (Boivin et al., 1999). This was despite stress, the possible pressure from advancing age and the common state of limbo. This man had clear ideas:

> "You've got to help yourself, nobody else can help you. They can advise you, but you've still got to do it within, from yourself." *Dave*

Mandatory or optional counselling

Fertility clinics have different protocols about how integrated counselling is within the multi-disciplinary team. Some require counselling before treatment and others offer it on an entirely optional basis. Counselling is fully integrated at The Fertility Centre in Christchurch, from which the sample of DI and IVF respondents were drawn from and had the majority of their treatment. There, people undergoing IVF, or any infertility treatment using a donor, see a counsellor before the consent interview with the medical specialist and afterwards, as required. This free and integrated approach to infertility counselling recognises the importance of addressing a number of key factors in the infertility and treatment experience of couples. About two thirds of respondents supported counselling being a requirement of the treatment work-up, although only half stated they would have attended counselling had it been optional. One woman said that if counselling was voluntary,

> "a lot of people would shy away from it, whereas if it is part and parcel of it you take as much of it as you want yourself. If you have to go, you realise they are not nearly as bad a people as you think they are. They are not cross-examining you. They are only there to help you." *Debbie*

Opinion is divided as to whether counselling should be compulsory or optional with infertility treatment. Having initial counselling should be a routine part of treatment according to Greil et al (1988:194), normalising and minimising the stigma of optional counsellor contact (Blyth, 1995:42). However, infertility patients are not well informed of the optional counselling they are entitled to (Douglas & Warbrick cited in Monach, 1994:1). There is also stigma attached to being seen not to cope with infertility and treatment, which can lead to few clients attending voluntary counselling (Strauss & Boivin, 2002; Monach, 1994). Discussing painful feelings may be avoided by some people, particularly men, as a coping mechanism (Collins et al, 1992; Deveraux & Hammerman, 1998; Lee, 1996; Mahlstedt, 1985; Stanton, 1991; Stanton & Dunkel-Schetter, 1991; Wright, et al, 1991; Zoldbrod, 1993).

Some authors (and respondents) prefer pre-treatment counselling to be optional, as not all people want or are seen to need help from professionals to cope with their infertility (Cook, 1987, Daniels 1992). Seven out of forty participants thought that contact with counsellors should depend on need and choice, while three others said that "at no stage" should counselling contact be made. As one woman said

> "I think counselling should be optional, I really do believe that." *Olivia*

The timing of counselling

The psychosocial issues, options to be considered, decisions to be made and therefore the counselling tasks will all alter over time (Daniels & Stjerna, 1993; Daniluk, 1991; Greenfeld et al., 1987; Reading & Kerin, 1989). The phase of the infertility pathway is a critical determinant of the issues addressed in counselling (Craig, 1990:491). Because there are great differences in the timetables of infertile people, counsellors need to determine which phase clients are in with their infertility journey, before setting specific counselling goals, then renegotiating these goals over time (Cooper & Glazer, 1994:363). Professional counselling should be available at initial diagnosis; while awaiting treatment; after a failed treatment cycle; when deciding to stop treatment; and after an unsuccessful pregnancy to deal with distress (Monach, 1994:5). Participants were asked to identify the critical stages of infertility when counselling would have been helpful. These times were at infertility diagnosis; after treatment failure; when options were perceived to be running out (leading on to stopping treatment); and after pregnancy loss. The first three are covered in more depth here, as they concern decision-making.

The shock of diagnosis

Diagnosis of infertility is a fundamentally shattering event, an unanticipated life crisis (Lee, 1996:76) in which many profound losses are encountered (see Chapter One). It is well-documented that counselling services need to be available at the time of infertility diagnosis (Appleton, 1990; Australian National Bioethics Consultative Committee, 1990; Batterman, 1985; Blyth & Hunt, 1995; Craig, 1990; Daniels & Stjerna, 1993; Daniluk, 1991; Daniluk et al., 1987; Ellis, 1982; Holbrook, 1990; Kings Fund Centre, 1991; Lee, 1995; Levin, 1993b; McWhinnie, 1995; Menning, 1979; Needleman, 1987; Read, 1995, Rosenthal, 1992; RTAC, 1988; Thorpe, 1994b).

> "When we first found out, it was like it took about eight to nine hours to hit me, and then it just hit me like a roller-coaster and I turned up to work and I sat at my machine and cried. I just couldn't stop crying." *Olivia*

Not only are people faced with the impact of what infertility means personally and within the relationship, but they are also faced with many new options to be considered. This includes considering whether to proceed with infertility treatment, and if so, what, when, and where. People may need to consider third party reproduction, such as sperm, egg or embryo donors, surrogates or gestational carriers, and the implications of these other people in their reproductive arrangements and their potential children's lives. They need to consider whether they are comfortable living without children, and whether adoption is a possibility. At this early stage, people usually seek information and solutions. They also need to find a way of adjusting to a diagnosis and coping with this uninvited identity. There are a multitude of issues and decisions to be faced at this time (Rosenthal, 1992:69), which create new strains at a time when emotional resilience may be low (Daniluk, 1991; Kee, Jung, & Lee, 2000). Diagnosis of infertility is often shocking.

> "This might be humorous for someone who may listen to it... A surgeon came to me in St. George's Hospital... with 'ha ha, guess what old son.' Maybe it was his way of trying to break some bad news nicely... I don't hold anything against him, but it was just sort of like some icing on the cake of an experience that was terribly bad right from the beginning." *Dillon*

Over half the respondents identified the diagnosis of infertility as an important time for counselling support. This included half the men and almost three quarters of women. Some said "there should be more publicity of counselling". This woman would have valued early infertility counselling.

> "One of the things is to be counselled properly in the beginning. I think that's really important... and to be able to feel that you can go and talk to someone if you're having difficulties." *Maureen*

This raises questions about how to best support people building up to, at the time of and after diagnosis. It is well known that most people have access and contact to counsellors *after* the initial shock of infertility diagnosis has passed (Batterman, 1985:50). People usually do not access infertility counselling services to assist them in clarifying their options and decision-making (Daniels & Stjerna, 1993:42). Accessing counselling services may be problematic at the time of infertility diagnosis for a number of reasons. The infertility work-up is medically focused, with a medical problem-solving approach to test and treat people for infertility. It does not aim to address the psychosocial issues involved with infertility. General practitioners and gynaecologists are often not attached to counselling services, nor are they necessarily familiar with what counsellors can offer and when or where to refer. Diagnosis can be protracted, or can be inconclusive in the case of unexplained infertility, which can make it difficult to know when to acknowledge infertility and seek help.

Counselling during this early stage focuses on the anticipatory work regarding treatment (Blyth & Hunt, 1995:63). Helping people to cope with the unexpected crisis of infertility (Burns & Covington, 2000:480; Shapiro, 1988:21) is a key component of counselling at this early stage. The tasks of counselling at the time of diagnosis, or first phase (Craig, 1990) are information-giving and aiding discussion about infertility, which leads to informed decision-making by the clients (Haker, 1998:130). I would add developing a flexible treatment plan. The aim is for clients to feel empowered and in control, especially during the taxing process of tests and treatments, so that they can exercise self-determination within realistic boundaries. This woman said,

> "It would have been really good for me to have had contact with either a counsellor or a social worker, probably at that first appointment when I went to see the gynaecologist... Just to make us stop and realise what we were beginning and that you have got choices and a chance to sit down together and be more informed, maybe take some preventative steps to maintain and look after yourselves a bit better, and you relationship... so counselling would have been very helpful." *Clare*

If people are considering the use of donor gametes, counselling explores the implications of involving a third party. The changing culture of secrecy surrounding the use of donor gametes, now means counselling addresses the issues involved for the three parties: donor; recipient individual or couple; and potential child, who cannot be involved in the decision-making process (Kententich, 2002:1). This includes discussion around the openness of the arrangement and deciding how open to be with the child and with others about using donated gametes (Boivin, 2002c:52). Creating a family through DI involves major challenges to the male partner, as his genetic continuity is lost (Daniels, 2002:32). This DI father explains:

> "I tend to feel, which is a bad thing that I really psychologically can't seem to get rid of it, that our child is more Anna's than mine, because she contributed more to it genetically." *Dillon*

Coping with treatment failure

The crisis created by unsuccessful infertility treatment can be lead to severe emotional reactions and needs (Dunkel-Schetter & Lobel, 1991; Wischmann et al., 2001). It is the *number* of treatment failures, rather than the years spent in treatment or peoples' ages, that predict personal distress and relationship conflict (Boivin et al., 1995; Diamond et al., 1999:163). Many authors have highlighted the need for counsellor follow-up and that outreach by counsellors is essential (Appleton, 1990; Australian National Bioethics Consultative Committee, 1990; Blyth & Hunt, 1995; Burns & Covington, 2000; Connolly et al., 1993; Daniels, 2002; Daniluk, 1991; Epstein & Rosenberg, 1997; Greenfeld et al., 1987;

Hammarberg et al., 2001; Holbrook, 1990; Kee et al., 2000; Kings Fund Centre, 1991; Levin, 1993b; Needleman, 1987; Newton et al., 1992; Read, 1995; RTAC, 1988; Shaw et al., 1988; Thorpe, 1994b). Negative results cause heightened distress, as this woman described.

> "It was our anniversary that we got the results... I went to Merivale... I don't even know what I was doing there... I knew I was driving down there. I knew I was wandering around, but I wasn't looking at anything... It was a weird feeling, totally weird, totally empty or something... I was sort of like a zombie." *Ann*

The period after treatment failure was seen as important for counsellor contact by over half of the women and one third of the men. The times specified for follow-up contact by a counsellor were quite variable. DI participants wanted contact between two and ten cycles, or between six months and a year of treatment. Most IVF respondents wanted earlier contact, between one and three weeks following a negative IVF result. This reflects the more invasive and stressful nature of IVF treatment, the fewer IVF cycles participants had and the greater number of participants who finished IVF treatment without a child. This woman talked about the impact of IVF failing.

> "The failure... It doesn't take one month - it takes months. And it's the acceptance inside of you that's the hardest part... You just can't let yourself bottle up into a wee ball. You've got to be able to express and let go." *Margaret*

There was an overwhelming call by 37 out of forty participants for *follow-up counselling* to be offered after a certain period of time on an infertility programme.

> "The only thing out of the whole thing personally that I think could have been of benefit was... ringing everyone a couple of weeks or a week after treatment (results) and saying 'hey, how do you feel? Do you want to talk about it?' Really, really important." *Sarah*

After treatment failure, counsellor's help people grieve, make difficult decisions about future treatment or alternatives, as well as support the couple relationship (Cooper & Glazer, 1994; Burns & Covington, 2000). The decision-making components of this phase (Craig, 1990) focus on revisiting the infertility treatment plan; giving information about options and referral; and reaching a realistic agreement about whether to proceed or not with further efforts to become parents. This may mean possibly intensifying efforts if time is pressured; having a break from treatment; considering alternative parenting, such as using donor gametes or adoption; or moving on from treatment without children. Other counselling tasks may include reviewing how the treatment cycles went; coping with the impact of chronic infertility; and dealing with any issues triggered by the outcome of treatment. Counsellors may have input into decisions relating to foetal screening, antenatal testing and the selective reduction of multiple pregnancies (Blyth & Hunt, 1995:64).

People who are desperate to conceive, and who persist with infertility treatment, raise other counselling issues at this time. Counsellors need to be more mindful of the emotional cost of intense perseverance in the fertility quest (Gordon & Barrow, 2000; Reading & Kerin, 1989). Several persistent participants had not sought additional counselling themselves, yet recommended counselling to others, such as this man.

> "They are on a steamroller type of thing where this is the be all and end all... When you're like that, I would say that you need some sort of counselling, heavy counselling!... Every time they go and don't succeed... they would get more depressed and more depressed and more depressed. That's what happened to us to a degree." *Anton*

Moving on from the hope of treatment

Deciding to stop infertility treatment can be more difficult than continuing, because of the lure of medical treatment options now available (Wischmann, 2002:25). "When to stop searching for answers, if none have been found. When to stop treatment, when to give up the all-consuming hope of a pregnancy is a very difficult decision to make. These dilemmas exaggerate the crisis and the emotional trauma of infertility" (Ellis, 1982:58). Regardless of the point at which treatment ceases, people need to feel that they have done their best to resolve their infertility (Wischmann, 2002:26) that they can live with their decision to stop. As one man said "we know we've done everything, we've tried everything"

(Dave). Counselling at this stage aims to bring some closure on the quest for a biological child, particularly if treatment has been unsuccessful, as this woman found.

> "I've actually had to start some counselling last year. That in itself has helped us, or helped me, accept what is happening in my body and accept that it is time to stop looking forward... And I am tired, I'm tired of moving forward." *Jade*

As everyone who starts infertility treatment needs to stop at some point, counselling should address the decisions and process of moving on (Appleton, 1990; Australian National Bioethics Consultative Committee, 1990; Blenner, 1990; Blyth & Hunt, 1995; Daniluk, 1991; Diamond et al., 1999; Kings Fund Centre, 1991; Levin, 1993a, 1993b; Menning, 1979; Newton, 2000; Paulson & Sauer, 1991; Read, 1995; Reading & Kerin, 1989; RESOLVE & Aronson, 1999; RTAC, 1988; Schmidt, 1998b; Sewall, 2000; Shapiro, 1988; Thorpe, 1994b, 1996; Wischmann, 2002). There are additional counselling issues and decisions involved in adoption (Diamond et al., 1999; Valentine, 1988), and in choosing a life without children at the end of infertility treatment (Diamond et al., 1999; Sewall, 2000). The transition to pregnancy and parenthood after infertility treatment has also been highlighted for counsellors (Abbey, Andrews, & Halman, 1994a, Abbey et al., 1994b; Appleton, 1990; Australian National Bioethics Consultative Committee, 1990; Baetens, 2002; Burns & Covington, 2000; Glazer, 1990; Sandelowski, 1993).

About one third of participants, especially those using DI, thought counselling was important when options were perceived as running out. "When you think it may not work" was mentioned as a good time to have counsellor contact, reflecting the concern of being left at the end of treatment with no children. Being without options is a matter of personal interpretation, rather than medical definition (Greil, 1991:101), as people need to decide for themselves whether they have run out of options. Some IVF respondents thought there should be a counsellor appointment, similar to a medical review appointment, after publicly-funded treatment cycles were completed. One woman said that

> "seeing someone six months later is a good thing, for counselling... It might be a better thing if it was compulsory... just to see how they are coping... They might find out a lot of things that they didn't realise were there, they could have shut off from." *Ann*

Because the interface of infertility with an individual's life is so personalised, the counselling approach needs to be neutral in supporting client's decision to continue or stop medical treatment, carefully countering the social bias toward having children (Braverman, 1997; Diamond et al., 1999). Counsellors have been challenged to restrain from an impulse to hold out continuing hope for 'one more try' in the face of failure, when people are tentatively indicating a need to terminate treatment (Read, 1995:87). While it may be helpful for counsellors to address the issue of setting reasonable limits on the pursuit of medical infertility treatments (Burns & Covington, 2000; Sandelowski, 1993), this may be difficult. As found in Chapter Three, people's treatment limits change and often get extended. Commonly, people cannot predict how long or to what lengths they will go at the start of their infertility treatment. Rather than setting limits on the pursuit of a pregnancy, it is probably more realistic for infertility professionals to give information and support (Daniluk, 2001b).

It is important to be active in decision-making, rather than live in a state of psychological limbo (Shapiro, 1988). For those people whose lives have been on hold, with all other plans halted in the pursuit of biological parenthood, or in paralysing limbo, counselling serves a valuable purpose in re-activating choice and realistic control over individual and joint life goals (Daniluk, 1991:319). Counselling is useful in working through ambivalence or 'decisional drift' (Sewall, 2000:421). Because limbo is relatively common (see Chapter Three), counselling can assist people to reach a decision to either resume treatment again or clearly move on. (Zoldbrod & Covington, 2000:337). One DI couple were in limbo about whether they would stop or restart treatment. They were also concerned about recognising these factors at the right time, and found both counselling and medical advice helped their decision-making.

> "Once that is a definite no, then I can see that I'll need help to accept that that's the way things are, and the

> way they are going to be... It's not going to be plain sailing." *Charlotte*

If people are still childless when they stop infertility treatment, counselling needs to consider the personal meaning of living with an unfulfilled major purpose. This third phase of counselling (Craig, 1990) involves helping people make the transition to childlessness positively. The counsellor tasks during this phase of resolution, or moving on (Covington, 2000a; Diamond et al., 1999; Sewall, 2000) include firstly, grieving the losses experienced; secondly, guiding their decision-making; and thirdly, 'deconstruction' of the old infertility experience and refocusing on life ahead by 'reconstructing' a new reality and future (Newton, 2000:112). This means helping to develop a different identity and new life meaning, in order to accept and find fulfilment in a life without children (Boivin, 2002c:53). Counselling at this time can 'reframe' the decision to end treatment as a success rather than a failure, so that people can move on with the sense that they have taken charge of their lives and made real decisions with consequences (Read, 1995:80). The transition from 'infertility patient' to what is sometimes called 'childfree' status (Carter & Carter, 1989) is both symbolic and significant (see Appendix 19). Several participants noted advantages to life without children. One woman said that having children:

> "would really be quite a shock... because you really would have to completely adjust your lifestyle. It's a very scary thought, very scary! I'm sure it would be a very positive change long-term, but it's really hard to imagine it... It would certainly curtail all our current sort of flare of activity." *Lois*

Deciding to end unsuccessful infertility treatment can trigger a complex series of issues for couples (Newton, 2000:111). The decision about how far to go in one's efforts to have children is an individual one (Berger et al., 1995:278), and partners may not arrive at the point to move on from treatment at the same time, or for the same reason, causing pressure and conflict. One partner may be determined to become a parent and the other equally resolute about stopping treatment. There may be disagreement over the acceptability of alternative methods to build a family, such as donor gametes or adoption, disrupting genetic continuity to one or both partners. Counselling can assist people to talk about their true feelings about moving on, to avoid wrong perceptions within the relationship (Stammer, Wischmann, & Verres, 2002). Infertility counselling can help couples deadlocked in different positions reach a compromise about moving on from treatment (Cooper & Glazer, 1994; Daniluk, 2001c; Sewall, 2000).

Self-disclosure by the counsellor

Significantly, it would have made some or a lot of *difference* to over three quarters of the participants if they had known that the counsellor had a personal experience with infertility. One third said knowing infertility was a shared experience would make a lot of difference. More IVF respondents than DI, and slightly more women than men said it would make a difference to them. Almost half, mainly IVF women, said that with a personal experience, the counsellor would be "more understanding and empathetic". One quarter said that knowing someone has a similar problem makes it "easier to relate". Several people added that knowing about the counsellors situation would have "normalised" their own infertility situation; given the counsellor more "credibility"; 'would lead to a "real exchange of information"; and that knowing would give "hope and reassurance".

> "It would have made a vast difference to have been interviewed by a counsellor who had had experience with this and commented that they'd had personal experience... I possibly would have been a lot more open about it, I would have understood it much more."
> *Dillon*

Only six people said counsellor disclosure would make no difference to their experience and value of counselling. Of these, four were men and two were DI women. Counselling was said to be a professional matter of skill, rather than a personal one, and that the counsellor needed to be independent. Others said that personal experience should not be a prerequisite as it depends on the individual counsellor concerned. These responses raise questions about personal disclosure by professionals. This is an issue that is often avoided to maintain clear and neutral boundaries and to minimise counter-transference.

> "I'm probably a typical male that can be very pig-headed at times... I'm not saying that every counsellor that's involved with the IVF clinic should be infertile... I may have had more respect and more openness towards you, because... you were going through the same heartache and the same loss of identity and loss of direction as we were... It's that sort of rapport that may have made me feel a little more at ease." *Samuel*

Some literature has dealt with the counsellor's personal experience with infertility. To work ethically and professionally, counsellors need to be truly themselves (Reiter-Theil, 1998:146) and must understand their own 'lived self' and use this self-awareness of experience to facilitate the client to know their own truth (Lovelie, 1982:122). While 'insider understanding' that infertile therapists have for their clients is regarded as positive, counter-transference can be a danger if over-identification with clients occurs (Peoples & Ferguson, 1998:218). Thus, any emotional work that needs to be done on personal issues must obviously occur away from the client relationship (Crawshaw, 1995:49).

Infertility is an experience people can choose to be very private about. It is an experience that can divide people into insiders and outsiders. Boundaries between the personal and professional need to be thoughtfully and purposefully placed (Applegarth, 2000:98), to both protect and empower the client. If the lived experience of the counsellor is such that it can be drawn on for the benefit of the client, then professionalism can include the conscious and careful disclosure of the personal to normalise a private experience, share power, and encourage rapport and trust.

> "About counselling, especially in the early days, I would really loved to have had somebody that I could have sat down and talked to... I thought I was the only person in the world who was having treatment... I didn't know where it was going to go to, how it was going to end, what you have to go through, how long it could take, how long it might not take... And it's all very well after (having a child), you don't really need somebody... You're happy and you're on a different level, on a different plane." *Anna*

Conclusion

Professional infertility counselling has an important role to play in assisting people with the demanding range of decisions required along their infertility pathways. Implications counselling aims to help people make informed and considered decisions regarding future treatment options, including donor gametes, adoption and childfree living. Counselling tasks vary, depending on the client's infertility phase and treatment status. In working through the meaning and implications of people's choices as individuals, couples and as a future family, counsellors essentially help people to make their own decisions (Appleton, 1990:844). Most decisions navigating the infertility treatment treadmill were made by participants on their own, or with input from their doctor. While decision-making input from counsellors was valued, few people accessed counsellors for this purpose. This raises important questions. How can counselling be encouraged at known critical times like infertility diagnosis, after treatment failure, and moving on from treatment? How pro-active should counsellors be with follow-up? How do counsellors with a personal experience of infertility safely integrate this into the client-relationship?

> "Maybe I would have been able to accept it more easily, you know, talk about it." *Glenys*

The next and final chapter is a discussion and conclusion of the issues raised in this research study on infertility treatment decisions. Questions arising from the research and specific directions for infertility counsellors and other infertility professionals are highlighted in this concluding chapter.

CHAPTER 6

Infertility Treatment Decisions: Conclusions and Implications

> "I'd like to thank you for the opportunity to take part in your survey Anna. I hope that what we've said is of some small use to you, especially if you throw it into the mixing pot with several other surveys, there might be a thread of commonality or there might be some degree of substance that you can use. I guess for me it's another opportunity to think about it, to look at it and to be open about it with someone who understands the issues." *Nicholas*

This thesis has aimed to highlight on how people make infertility treatment decisions, from the time that infertility is first diagnosed, through the complex maze of treatments available, until a decision to stop treatment is made, either with children, or without. This chapter concludes the thesis by putting assisted reproduction within a context of increasing choice and dilemmas. The key results are revisited, with their implications for people experiencing infertility, then questions are raised and directions offered for both professional practice and psychosocial research into infertility.

Choice in assisted reproduction

The quest for a baby is driven by demand and supply (May, 1995:232). The proliferation of infertility treatments now available has led to more alternatives and more dilemmas (Adler et al., 1991:111). Both parenthood and the pathway through infertility treatment have progressively become a matter of choice and planning (Sutton, 1998:59), although not for all (Bartlett, 1994:211). Up until the 1980's, accepting a future without one's own children was simpler, because there were fewer options available and they were less likely to be successful. Infertility treatments, like *in vitro* fertilisation (IVF) and intracytoplasmic sperm injection (ICSI), have enhanced reproductive choice, offering the very real possibility of one's own child. While increasing age is an unstoppable fact, time passing no longer provides the treatment containment it once did (Lee, 1996:68), with the 'lure of a cure' (May, 1995:236) through donor egg, donor embryo and surrogacy programmes.

This extension of medical treatment has both prolonged hopes and made knowing when to stop treatment harder to accept (Schmidt, 1998b; van den Akker, 2001). Hope is an important motivating concept with infertility treatment. It represents the power within the self, which mobilises one to move beyond the present situation and envisage a better personal future (Herth, 1996:747). However, hope becomes a double-edged sword (Daniluk, 2001c; May, 1995) - offering the very real possibility of having a child on one hand, but demanding an ongoing, significant personal cost, with no guarantees of that child, on the other. The very existence of these possibilities makes the decision not to have any treatment, not to choose a particular option, or not to continue having treatment, more complicated and potentially more conflicted (Braverman, 1997; Sandelowski, 1991; Tymstra, 1989) than staying on the treatment treadmill (Sewall, 2000:417).

> "Once you were on, it was sort of like you couldn't stop. You had to do this to go through that. We trusted them, that they knew what they were doing and the way they were speaking to us, it was curable - you know, it was easily fixed." *Tama*

Seeking medical help and being more informed and involved in the planning and timing of treatment is a way of *consciously* taking control in the face of infertility (Domar et al., 1990; Read, 1995; Woollett, 1985; Zoldbrod, 1993). Choice and autonomy are deeply embedded within our culture (Michie & Cahn, 1997:161). Women's 'right to choose' over their body has been symbolic of feminist liberation for decades. However, these choices are complex. Clearly people have the choice not to be treated for infertility. But what sort of choice is it to remain involuntarily childless in a social context, which stigmatises infertility, when assisted reproduction offers the chance to become socially accepted parents, fulfilling a major personal goal (Baker & Bertenshaw, 2002; McNeil, Varcoe, & Yearly, 1990)? In addition, simply because infertility treatments are available, social and medical pressure exists to use them (Michie & Cahn, 1997:162).

People are valued as active agents, capable of making decisions about their lives, in spite of the loss of control brought about by infertility (Kirkman & Rosenthal, 1999:31). As such, they have the right to decide whether to undergo infertility treatment in an effort to become parents. At the same time, people need to accept the limits of what their bodies and medical science can, and cannot, do in achieving a successful pregnancy. People need to feel they can make decisions they feel they can live with, based on their personal needs and individual realities (Daniluk, 1996:94). Individual well-being needs to be the goal of reproductive medicine and infertility counselling (Sewall, 2000:421). The ideal is a meaningful, satisfying and rewarding life, with or without children.

> "The bottom line, I guess, is to be thankful for what you've got. We are all in some shape or form a statistic of something, and unfortunately ours has to be the infertility. Don't put it behind you as a lot of people will tell you to, because it will never go away. If you get involved with groups and you can actually help someone, divert them from the path that we went down. You just hope that you can give them some words of encouragement, wisdom, hope and that all is not lost." *Martin*

Key findings and their implications

This study uncovered a number of significant results. Because of its longitudinal nature over two and a half years, it was possible to track the status and movement of people's infertility treatment. Information gathered from three time snapshots allowed for the development of an original model of treatment status. This model showed that people fell into four main treatment groupings: 'active' for those having active treatment; 'non-active' for those having a break between cycles, with the intention of resuming treatment; 'in limbo' for those uncertain about whether to resume treatment or quit altogether; and 'stopped' for those who had clearly ended their treatment and moved on, either with or without children. There was considerable movement between these different treatment statuses, depending on opportunity and readiness. People were found to generally move from being active in treatment, through non-active or in limbo periods, towards stopping treatment. The model allows for the nature and movement of people's infertility treatment to be better recognised and understood by those having or contemplating infertility treatment, and those who are involved in providing infertility services.

It was found by analysing participant's treatment status over time that breaks between treatment cycles and uncertainty about continuing or stopping treatment are relatively common. In fact, half of the participant couples were non-active or in limbo during the two and a half year research period. However, being non-active or in limbo is under-recognised professionally and in the literature. Of particular note, people in limbo, who find themselves undecided about resuming or stopping treatment, may not realise how widespread this is. Those paralysed by decision-limbo may not know how to get through the impasse, reach agreement, or where to seek support.

The study found obvious and predictable gender differences in the motivation to start, continue and stop infertility treatment. The more surprising influences were the differences between parents and childless respondents. Women tended to make these decisions if they were in a childless relationship (also reported by Becker, 2000), while parents made these decisions more jointly. In assuming the role of 'primary mourner' (Burns & Covington, 2000:13) and primary decision-maker, childless women bear an unequal share of the couple's grief and responsibility for the direction of treatment for infertility. There is some evidence to suggest that the further along the treatment treadmill women go, that the harder it is to relinquish the desired identity of mother-to-be (Berg & Wilson, 1991; Carter & Carter, 1989; Link & Darling, 1986; Sewall, 2000. While rarely do both partners share the same emotional reactions about continuing or stopping infertility treatment (Braverman, 1997; Peoples & Ferguson, 1998), the challenge remains for men and women to understand each other in the experience of infertility - in facing the myriad of demands and decisions together.

'Anticipated decision regret' (Tymstra, 1989) was found to motivate people to start and continue infertility treatment. Many participants expressly made decisions to avoid later regretting not having taken a certain option.

This generally led people to extend their treatment limits over time, particularly emotional strain, age, and money spent, until they felt satisfied with their individual 'best effort'. If successful in terms of having a child, this effort would be well worth it and if unsuccessful, people are more likely to feel satisfied with their effort of trying, aiding resolution.

'Perseverance' was also found to be a common feature of those continuing with infertility treatment. Many respondents suggested that people persist with treatment until they personally feel they have enough children or have had enough treatment. It was also recommended that people avoid becoming obsessive in their quest for children, which could damage the relationship or other aspects of life - instead accepting that they have to stop sometime. Persevering with treatment needs to be put within realistic bounds (Vercollone et al., 1997), including what is medically warranted; what treatment can be afforded; how much stress and failure can be coped with; whether one partner in the relationship is having second thoughts about continuing; and side effects on health. Treatment cannot be continued indefinitely, and knowing when to stop is a key ingredient in 'healthy decision-making' (Gordon & Barrow, 2000:504).

Stopping treatment without children is one of the most difficult decisions to be faced in infertility treatment (Saunders, 1998:153), as the preliminary study found. Exiting the medical quest for a child is likely to be emotionally difficult and prolonged. The longitudinal model of treatment status showed that stopping treatment is not always a final decision (Diamond et al., 1999:165), as some participants repeated treatments or tried new options. Participants were found to stop infertility treatment after they had children; because of advancing age; the woman's decision to stop; and financial pressures. Surprisingly, half the participants needed no medical information to make their decision to stop treatment. When respondents stopped treatment and moved on they experienced, or anticipated feeling, freedom from uncertainty; being able to plan ahead; being able to get on with the rest of their life; and if childless, emotional strain and concern about their future.

The implications of stopping infertility treatment are greatest for those who do not have children. While assisted reproduction is often offered as the solution to the problem of infertility, treatment is not perfect and many people do not become parents (Leiblum, 1997; Paulson & Sauer, 1991). However, pregnancy is not the only way to measure success after infertility treatment (Berger et al., 1995; Sutton, 1998). Learning to live with infertility is deeply challenging, requiring time and a conscious shift from pain, sorrow and loss (Sewall, 2000:417), to a new self concept and anticipated future. As several participants noted, facing infertility brings strength, learning, perspective, togetherness in the face of adversity and the opportunity to re-order what is important in life. The reclaiming of one's life back, after years of feeling as if it were on hold during infertility treatment, can bring relief and a sense of renewed control (Braverman, 1997; Daniluk, 2001a:). A 'childfree' life can be rich, varied and satisfying, despite the lack of children (Carter & Carter, 1989), as people put their energy into their relationships, careers, nurturing other people's children, interests or special projects.

The key counselling roles, specified by three quarters of participants, were assistance with coping after treatment failure; giving information; and support. Counselling input into coping during treatment; after pregnancy loss; with emotional strain; depression; and relationship issues were also highlighted by half the respondents. Men were found to value counselling's information-giving role, while women preferred help to cope with treatment, anxiety and pregnancy loss. The strongest response from participants was an overwhelming call for follow-up contact by counsellors after a certain period of time in treatment, which is not routinely practiced.

A surprise result was that participants, notably IVF, did not find counselling helpful for their infertility decision-making and moving on from treatment. This was partly because of the limited counselling they had and partly because they made 'autonomous' decisions (as Sjogren & Uddenberg, 1988, found with other medical decisions) or with input from their doctor. However, half the respondents, particularly women and those having DI, wanted counselling input with their infertility decision-making. Even more, three quarters, would have appreciated counselling involvement with their future options and the process of moving on from infertility treatment. But few respondents received these elements from the counselling they had. Neither, interestingly, had they sought out further counselling for these matters, even though they knew of its availability at no cost. It is significant that participants made infertility decisions without support, considering that almost half of them had periods of limbo during the study, some of which were very prolonged.

Questions and directions for professionals

What difference does this research make to those professionals providing infertility services? There are a number of points that emerged for professionals, including counsellors, working in the area.

> "I just wish that there was an A to Z book available that you could get from the library that said 'this is what may happen to you as an infertile couple'... And if we can see a pitfall coming... then we can look in our little instruction book and say 'avoid path A and take path B and you'll avoid the pitfalls that are in path A'... But I guess the only way you're going to get that sort of knowledge is by doing research work like you're doing. And I hope that maybe some of the pitfalls that we are going through, the problems we're having, you can put them in your 'A to Z of Infertile Couples - How to Survive in the Cruel, Hard World of Infertility', and until that happens I guess we're going to be in the same sort of hole that other people are, just wandering around in a daze." *Samuel*

Firstly, informed and collaborative infertility decision-making must involve the individuals concerned in 'partnership' with the infertility team (Bitzer, 2002; Deber & Kraetchmer, 1995; Deber, Kraetschmer, & Irvine, 1993; Greil, 1991; Sawicki, 1991). It has been reported that people feel more satisfied with their decisions, if they are involved in decision-making (Chapman et al., 1995:232). This is because people can better fit their preferences (Frank, 1989) with their goals and values, and the feeling of empowerment gained from participating and choosing. The key issue is how professionals can assist people to make positive, informed decisions about their future infertility treatment and related choices (Glazer &

Cooper, 1988), which are 'personally satisfying' (Beach, Townes, Campbell, & Keating, 1976). This can include:

- providing effective 'patient-oriented' education as a means of informing people about their options (Chapman et al., 1995; Stewart et al., 2001);
- drawing up flexible plans (Menning, 1984), with time to reflect during decision-making (Sjogren & Uddenberg, 1988), which are regularly reviewed (Oke, 1999) and amended;
- providing detailed information about the tests proposed, treatment options, knowing one's personal chance of treatment success and reviewing each treatment cycle (Berger et al., 1995; Frank, 1990a);
- coaching people about different models of decision-making (Janis & Mann, 1977);
- supporting people in the treatment choices they make, even if these choices appear to have a remote chance of success (Daniluk, 1997);
- 'emotional inoculation' for post-decision setbacks (Janis & Mann, 1977), for example, treatment failure;
- helping people to gain control over their treatment choices (Naish, 1994), setting flexible parameters around the treatment they are willing to undergo (Daniluk & Fluker, 1995); and
- referral to an infertility support group (Clifford, Flavin, & Duggan, 2001; Daniels, 2001; Labett, 2001; Paulson & Sauer, 1991; Shapiro, 2000).

Thus, the professional response called for is both complex and delicate, requiring consciousness of decision-making processes, and treatment motivators, such as anticipated decision regret and treatment perseverance.

Secondly, people who are not in active treatment, are generally under-recognised in clinic practice, unless they initiate requests for information, support or follow-up appointments. Only those having 'active' infertility treatment receive much support from fertility clinics, which focus their considerable efforts on facilitating conception. Those who are 'non-active' and having a temporary break from treatment may receive limited support, as part of anticipating and managing the flow of future cycle numbers.

Those who are 'in limbo' have the greatest needs for assistance, as people are stuck, commonly with disagreement or depression. The key issue is how professionals can best support people caught by decision paralysis to reach clarity and readiness, so they can either re-activate or stop their treatment. This may involve:

- encouraging follow-up appointments to provide information and personalised prognosis on success rates;
- therapeutic counselling to coach people on different models of making decisions and assist with disagreement (Daniluk, 2001c) or depression (Hunt & Monach, 1997); and
- an effective, properly resourced system of sensitively contacting patients who are uncertain about returning to treatment to facilitate treatment re-engagement or discontinuation (Emery et al., 1997).

People in limbo should not left to drift by treatment providers.

Thirdly, stopping infertility treatment without children requires special attention from infertility professionals. Abandoning the quest for children without fulfilling that dream is likely to be prolonged, ambivalent and painful. People may need assistance to extricate themselves from the medical system when they no longer have the emotional, personal or financial resources to pursue further medical solutions (Daniluk, 1997). This is particularly so for women (Braverman, 1997; Conway & Valentine, 1988; Daniluk, 1991; Jones, 1989; Zoldbrod, 1993). The key issue is how to support people moving on from treatment without children (Thorpe, 1996). This can include:

- medical appointments leading up to the decision to stop treatment (Frank, 1990a) - to review previous treatment; evaluate future options and their prognosis; and give a medical recommendation (especially with IVF), if chances of success are poor or if continued treatment places people at high risk physically or psychologically (Daniluk, 2001a; Paulson & Sauer, 1991);
- 'parallel counselling appointments' (Lalos, 1999) leading up to and following the decision to move on - to evaluate options for people's futures, including adoption and living without children; support people through the grief of losing 'an emotionally conceived child',

and navigate a journey into an uncertain future (Braverman, 1997), involving the transition to and reconstruction of a positive new phase in life (Carter & Carter, 1989; Cook, 1987; Crawshaw, 1995; Daniluk, 1996; Sewall, 2000); and

- referral to infertility support groups, such as the 'No Kidding' group (Clifford et al., 2001)

While obviously the primary goal of assisted reproduction is to enable people to have children, surely a simultaneous responsibility exists for those who stop treatment without children (Thorpe, 1996). Infertility treatment providers need to help people survive the life crisis of infertility, adapt to bad news (Lalos, 1999) and make decisions that will lead to a full life after the exhausting experience of infertility (Clapp & Adamson, 2000), so that they can live with relative peace and satisfaction around the 'infertility issue' (Carter & Carter, 1989; Entwistle, 1992; Harkness, 1987; Seibel, 1992).

Fourthly, people require more help after the failure of infertility treatment. The outcome of each treatment cycle is more likely to be negative than positive, so failure is a realistic part of undertaking any medical treatment (Paulson & Sauer, 1991). It is the number of treatment failures, rather than the years spent in treatment, that predict personal distress and relationship conflict (Boivin et al., 1995; Diamond et al., 1999). The key issue is how infertility professionals can best support people after treatment failure, which can involve:

- other members of the multi-disciplinary team actively and regularly promoting counselling services;
- an effective, well-resourced system for counsellors to initiate follow-up after a failed cycle or after a certain period of time in treatment (Appleton, 1990; Covington, 2000a; Daniels, 2002; Thorpe, 1994). Participants overwhelmingly called for counsellor to contact those on the DI programme after six to twelve months, and those on the IVF programme more frequently; and
- counselling after treatment failure to: help people grieve; assist with difficult decisions about future treatment or alternatives; and

support the couple relationship (Cooper & Glazer, 1994; Covington, 2000a).

Fertility clinics have a responsibility to support that majority of people who have a failed treatment cycle.

Fifthly, of a more personal nature, feedback from three quarters of participants indicates that it would have been helpful if counsellors self-disclosed a personal experience with infertility. Disclosure was perceived to aid rapport, trust, understanding, empathy, and counsellor credibility and to normalise the experience of infertility. The integration of truth and enhanced self-knowledge into professional practice has been supported (Lovelie, 1982; Reiter-Theil, 1998), but caution is required to prevent over-identification with clients (Crawshaw, 1995; Peoples & Ferguson, 1998). This has implications for the counsellors with a personal experience of infertility and for other members of the fertility team who may as well, raising questions about whether professionals feel comfortable with disclosing such personal information, how and when to do this safely.

Questions and directions for research

Little research has addressed patient decision-making in the medical arena (Holmes-Rovner et al., 1996; Rothert et al., 1990). Much of the published psychological literature on infertility has been quite atheoretical (Newton, 2000:104), including that which seeks to understand why and how infertility treatment decisions are made. The process of medical care usually does not consider the reproductive decision process (Johnston, 1993:31). The field of assisted reproduction needs an analysis of medical decision-making (Banta, 1993:60), as infertility treatment involves increasing numbers of ongoing, complex choices. More research is needed in the neglected area of infertility decision-making processes (Callan, 1987; Daniluk et al., 1993; Frank, 1990a, 1990b; Greil, 1997). It would also be useful to assess how effective different models of decision-making are to people at different stages and statuses of their infertility journey.

There is also a need for more knowledge on the reasons, process and outcome of stopping infertility treatment, particularly for those who are left childless (Daniluk, 1996:83). Even though every person or couple who starts on the infertility treatment treadmill has to stop at some point, there has been a noticeable lack in the literature on how and when to do this. There is so much interest in the production of reproduction, that stepping back from infertility treatment does not have the same social, financial, scientific or personal attraction to researchers and writers. This is despite the reality that approximately half of those who have had treatment for infertility remain involuntarily childless (Daniluk, 2001a:122). Related to the further research on stopping infertility treatment without children, Johnston (1993:34) encourages researchers to focus more on effective strategies for dealing with the crisis of infertility, including an assessment of positive emotions, rather than the usual bias towards distress.

Challenges have been issued about how psychosocial infertility research is conducted. People experiencing infertility are social actors in a 'socially constructed life crisis', Greil notes in his critical review of psychosocial infertility research and more effort is needed to reach understudied portions of the infertility population, including non-treatment seekers, non-whites and lower socio-economic groups (1997:1679). People who are involuntarily childless who choose not to go through established fertility programmes are rendered almost invisible, yet they are important to listen to and understand (Koch, 1993). Recruitment of people following up failed treatment cycles and finishing treatment has been reported as difficult (Adler et al., 1991, Callan, 1987; Mahlstedt et al., 1987), as childlessness after infertility treatment is emotionally painful and usually people wish to get on with their lives. It would be useful to have positive feminist discourses about women who choose to pursue infertility treatment (Sandelowski, 1990a; Ulrich & Weatherall, 2000). Given the scant amount of research and writing on men's experiences with infertility, compared to women (Daniluk, 1997:109), and their decisions, it would be helpful for a man's perspective on infertility to be looked at in more depth, (such as Morse, 2001). Little is known of the differential effect of class, race and religion, for men over time (Hollerbach, 1980; Zoldbrod, 1993).

There is a real need for more infertility counsellors to be involved in research (Covington, 2000a:488) on the psychological and sociological aspects of infertility, the impact of assisted reproduction on people's lives, and the need for and usefulness of counselling interventions (Boivin et al., 1999:1390). The small population of Aotearoa-New Zealand means predictably limited numbers of researchers focusing on infertility, with no other known research on the issue of decision-making or moving on from treatment. However, there are a handful of steadily published researchers in the psychosocial aspects of infertility, notably Ken Daniels and Vivienne Adair. Sally Abel, Maureen Baker, Rachel Bertenshaw, Jenny Blagdon, Penny Brander, Ian Burn, Rachel Clifford, Sandra Coney, Annette Dixon, Winnie Duggan, Joi Ellis, Anne Else, Jude Flavin, Katrina Hargreaves, Robyn Irwin, Ruth Mortimer, Christine Rogan, Anna Rumball, Sue Saunders, Robyn Scott, Karyn Taylor, Miriam Ulrich, and Ann Weatherall have also published or presented. FertilityNZ has also been involved in infertility research. Aotearoa-New Zealand has been at the forefront internationally in recognising children's right to know their genetic origins, whether from birth parents, sperm or egg donors (Adair, 1998; Adair & Dixon, 1998; Adair & Rogan, 1998; Daniels, 1994, 1999; Daniels, Gillett, & Herbison, 1996; Hargreaves, 2002; Rumball & Adair, 1999). This has had drawn worldwide interest and generated further study into related topics.

"No research is carried out in a vacuum" (McRobbie, 1982:48). The topic of infertility decision-making is pertinent - because increasing numbers of people are undergoing an increasing range of infertility treatments involving increasingly complex and demanding decisions, over a longer period of time. It is also pertinent because it has not been adequately attended to professionally or in the literature, compounding the silent, individualised nature of infertility treatment decision-making. While it is recognised that people need to make informed, active decisions about their own infertility, it is also recognised that professionals providing fertility services need to be more mindful and supportive of decision-making processes and dilemmas along the infertility treatment treadmill - in which the 'best choice' is not always clear.

Qualitative research was found to be an appropriate and effective way of studying how people make infertility treatment decisions (Mays & Pope, 2000; Pope & Mays, 1995). The preliminary study used purposeful sampling with those who were understood to have moved on from treatment, and random cluster sampling in the main study (Mays & Pope, 1995:44), with those who had undergone an average to a higher number of treatment cycles in DI and IVF. The method of interviewing provided a mass of insightful data, which systematically and rigorously applied content analysis to draw out themes and patterns (Pope et al., 2000). This data was in part quantified to provide summaries and highlight variable influences, such as gender, parent status and treatment type. The longitudinal nature of the research was invaluable (Beckman, 1978:76) in tracking the changing treatment statuses of participants. Without these three snapshots over two and a half years, the original model of treatment status would not have emerged.

Ethically as a feminist social worker (Craig, 1991), one aim of the research is to contribute to the understanding of decision-making among both the community of infertile people and infertility treatment providers, adding to existing knowledge (Mays & Pope, 2000). The question of what to do with the research findings gathered is raised by feminist methodology. McRobbie (1982:13) refers to 'making talk walk' - meaning moving towards change through the talk of ordinary people, the writing of academics and the action of professionals. Through their involvement in the research, I trust the 52 participants in this study gained an opportunity to reflect on their infertility experiences and be genuinely heard. My hope is that these results and recommendations contribute to the knowledge of infertility decision-making for people negotiating the infertility treatment treadmill (through fertilityNZ), assisting them to make sense of their experiences and make informed choices on their own treatment paths. It is also hoped that the findings of the study will be helpful to professionals involved with providing infertility services (through ANZICA, the Australia-New Zealand Infertility Counsellors Association, and The Fertility Centre in Christchurch), increasing awareness, sensitivity, and active support around infertility treatment decision-making.

As a researcher, I have used myself as an 'instrument' to create the research (Patton, 1990:472). This involved being a facilitator, catalyst and negotiator in a flexible, responsive research role (Stokes, 1985), woven from the three strands of my involvement with infertility decision-making: researcher, counsellor and consumer. The research process has been a very personal and moving one, in which I have been privileged to listen to intimate, painful and joyful aspects of people's lives. In interviewing, recording, collating, and analysing the details of participant's lives, I have tried to find my own voice in honouring and expressing these stories. The creativity involved in such a task combines mind and heart, thought and feeling, theory and symbolic meaning, the personal with the political (Hera, 1995). In articulating and reading the stories, participants and readers are reminded of the normalcy of personal responses and the collective experience of infertility. This facilitates individual healing and social change. Finally, in the words of one participant,

> "I could certainly do without it." *Michael*

APPENDICES

Appendix 1: Glossary of medical terms and acronyms

Abortion A term describing pregnancy loss. Spontaneous miscarriage occurs regularly in the general population and when assisted conception is used (in up to 25% all pregnancies). Deliberate abortions for medical or social reasons are called termination of pregnancies (TOPs).

Adhesions Scar tissue from previous injuries, infection, endometriosis or surgery that forms in and around reproductive organs, possibly interfering with reproductive capacity.

Adoptive parents Parents who have children by adoption.

AID Artificial Insemination by Donor, now called DI.

AIH Artificial Insemination by Husband, an old technique that did not utilise sperm preparation or intra-uterine transfer, sometimes called AI. Now superseded by IUI.

Amenorrhoea Condition in women where there is an absence of menstruation, though menstruation can still occur.

Amniocentesis Procedure in the 14-16th week of pregnancy to detect possible foetal abnormalities, including Down's syndrome and Spina Bifida.

Anti-sperm antibodies A protein that can cause sperm to clump preventing or inhibiting fertilisation of the egg.

Anovulation Condition where there is a total absence of the menstrual cycle for at least 6 months.

ANZICA See Australia and New Zealand Infertility Counsellors Association.

Assisted conception A term describing treatment methods to assist conception. Also known as assisted reproduction.

ART See assisted reproductive technologies.

Assisted reproductive technologies Medical and scientific procedures with sperm, eggs and embryos to facilitate a pregnancy, including DI and IVF.

Australia and New Zealand Infertility Counsellors Association (ANZICA). Formed in 1989 as an independent professional body representing counsellors on RTAC, providing training, networking, developing standards of practice, and advocating counselling services to people accessing infertility treatment through the multi-disciplinary fertility clinics in Australia and New Zealand.

Azoospermia Condition ejaculate contains no sperm. Aspiration techniques may be able to recover sperm to be used with IVF procedures.

BICA British Infertility Counsellors Association

Biochemical pregnancy Pregnancy detected by a rise of pregnancy hormone but which fails to develop into a foetus detectable by ultrasound.

Biological child Child produced from sperm and egg of the birth parents.

Biological parents Parents who supply sperm and egg to create child.

Biopsy Surgical procedure to obtain tissue for analysis. Testicular biopsy can be used with men to assess the status of the testis.

Birth parents Biological parents of adopted child.

Blastocyst An embryo about 5 days after fertilisation when it is ready to implant in the endometrium.

Body mass index (BMI) Relationship between weight and height. Implications for fertility exist if weight is outside normal range.

Cervix The lower part of the uterus that connects with the vagina.

Childfree living A resolution to opt for a positive lifestyle without parenting after a period of infertility.

Clinical pregnancy Positive pregnancy result, diagnosed by measuring levels of Beta hCG (human Chorionic Gonadotrophin) and by ultrasound scan. May include problem pregnancies e.g. ectopic pregnancy.

Clomiphene citrate An oral antiestrogen drug commonly used to induce ovulation in women (Trade names are Clomid and Serophene).

Conception The union between sperm and egg resulting in an embryo.

Contraception Methods to prevent conception e.g. condoms, the pill.

Cryopreservation Deep-freezing process with liquid nitrogen, to preserve and store sperm, embryos and more recently eggs.

Cumulative pregnancy rate Rate of pregnancy over time.

Delivery rate per cycle Arguably the most important way of presenting statistics of treatment success, as opposed to pregnancy rate per embryo transfer or DI (without the miscarriage rate taken out of it).

Domestic adoption Adoption of a child from the same country as the adoptive parents.

Donor A person who offers his or her gametes (sperm or eggs) or embryos for the use of someone else (a recipient). With sperm, the procedure is called donor insemination, donor IUI, donor IVF or donor GIFT. With eggs, the procedure is called donor egg. A donor can be anonymous or personally known to the recipient.

Donor egg Eggs aspirated from the ovaries of a fertile woman are donated to an infertile woman to be used in IVF with male partner's sperm. See egg donation.

Donor embryo Embryos from the sperm and egg from one couple are donated to another couple or woman (usually after donor couple has finished treatment).

DI See donor insemination.

Donor insemination Process of placing sperm from a donor (a man who is not the woman's sexual partner) into the woman's reproductive tract, to bypass male infertility or a sperm-linked genetic abnormality. Any resulting child will be biologically related to the woman, but not to her partner (unless a known donor from the partner's family is used).

Donor sperm Male donor with good sperm quality and function donate sperm to be used in donor insemination cycle

Drug regimen For the stimulation of multiple ovulation, hormonal doses are administered, usually with ultrasound monitoring and blood tests.

Early menopause Where the menstrual period ceases due to premature ovarian failure before the age of forty.

Ectopic pregnancy A pregnancy where the fertilised egg implants not in the uterus, but usually in the fallopian tube, threatening rupture of the tube and requiring urgent surgery.

Egg The female reproductive cell, also called an oocyte or ovum.

Egg pick-up Part of the IVF, in which the woman's eggs are aspirated from ovarian follicles using an ultrasound guided needle through the vaginal wall, usually under sedation (rather than general anaesthetic). Also known as egg retrieval or harvest.

Egg donation If woman has stopped producing eggs, does not have ovaries or has a female-linked genetic condition, eggs can be 'gifted' by an altruistic or personal donor using IVF, fertilised by partner's sperm and transferred to woman's uterus.

Ejaculate Semen ejected from the penis during orgasm, which in most cases includes sperm.

Embryo A fertilised egg becomes an embryo, once it has undergone cell division until the eighth week of pregnancy.

Embryologist Highly trained and skilled scientist who handles human gametes and the resulting embryos, while they are outside the body.

Endometriosis Condition where endometrial tissue is found outside the uterus around the tubes, ovaries and abdominal cavity, often causing painful menstruation and fertility problems.

Embryo transfer Part of IVF when one, two or three embryos are introduced through the cervix into the woman's uterus. This happens two to three days after egg pick-up, when the embryos are between three and eight cells in development.

Fallopian tubes A pair of fine tubes attached to the woman's uterus and open to the ovaries, to transport sperm up and fertilised eggs down to implant in the uterus. Ectopic pregnancy can occur in tubes.

Fecundity The probability of conception occurring in a given period of time, usually a month.

Female factor A problem in the female reproductive tract, which may lead to infertility (for example, blocked tubes).

fertilityNZ Formed in 1990 as the NZ Infertility Society to provide those experiencing infertility with information and support; raise public awareness; network; represent consumers; and advocate for better services and funding.

Fertilisation The penetration of the egg by the sperm resulting in the development of an embryo.

Frozen embryo transfer Same process as embryo transfer in IVF, except the surplus embryos have been frozen in liquid nitrogen, stored for a period of time and then thawed prior to placement in the woman's uterus.

Foetus Embryo develops into a foetus, or unborn child, at about the 9th week of pregnancy.

FSA Fertility Society of Australia

Gametes A term for eggs and sperm.

Genetic counselling Provides information and support on prenatal genetic issues, where there is a heightened risk of birth defects.

Gestational Carrier Reproductive arrangement where woman agrees to carry a pregnancy created by a commissioning couples' sperm and eggs, then relinquish the child to them. She has no genetic relationship to child.

GIFT Gamete Intra-Fallopian Transfer in which eggs and sperm are replaced by laparoscopy into woman's fallopian tube to (hopefully) fertilise. Alternative to IVF.

Gynaecologist A specialist doctor who specialises in problems with the female reproductive system, usually an obstetrician as well.

HRT Hormone Replacement Therapy, containing oestrogen for menopausal women.

Human assisted reproduction Medically assisted treatment for infertility, similar to assisted reproductive technologies.

Hysterectomy Surgical removal of the uterus, and sometimes the ovaries and fallopian tubes.

Hysterosalpingogram HSG, A test for tubal patency, which involves an X-ray to image the womb and the openness of the fallopian tubes, which are filled by a radio-opaque dye.

ICSI See intracytoplasmic sperm injection.

Idiopathic infertility Infertility with an unexplained cause.

Implantation The embedding of the fertilised egg in the endometrium of the uterus. Ectopic pregnancies implant outside the uterus.

Infertility Condition where a woman or man has a disease of the reproductive tract that prevents conception, usually after 12 months of unprotected sexual intercourse, or successful birth after 3 miscarriages.

Infertility work-up Series of tests carried out to determine infertility cause.

Insemination Placement of sperm into a woman's uterus or cervix to facilitate pregnancy.

International adoption Adoption of a child from a country other than that of the adoptive parents.

Intracytoplasmic sperm injection ICSI is a micromanipulation technique to facilitate fertilisation when the sperm count or motility is very poor, by injecting a single sperm directly into an egg, with IVF.

In vitro fertilisation IVF, originally designed for women with tubal damage, and now used for an increasing number of infertility causes. A woman's ovaries are stimulated by complex drug regimen to produce multiple follicles. Eggs are recovered in an egg pick-up and mixed with sperm to encourage fertilisation. Up to three embryos are transferred into the woman's uterus 2-3 days later.

IUD Intra-uterine device for contraception, which has been implicated in pelvic inflammatory disease and tubal damage.

IUI Intra-uterine insemination, where prepared sperm is inserted into the uterus.

IVF See *in vitro* fertilisation.

Laparoscopy 'Keyhole' abdominal surgery allowing visualisation of tubal patency, condition of pelvis, tubes, womb and ovaries. It can also be used as microsurgery to repair damage, as an alternative to laparotomy.

Laparotomy Major abdominal surgery.

Male factor A problem in the male reproductive tract that may result in infertility (for example, low sperm count).

MESA Microsurgical epididymal sperm aspiration, or surgical removal of sperm from the epididymis for use with ICSI, avoiding need for ejaculation.

Menopause Cessation of menstruation caused naturally by aging (usually between 42 and 56 years), ovarian failure (can be premature), or surgical removal of ovaries.

Microsurgery Surgery that uses magnification, fine technique and suturing to get precise surgical results (e.g. in tubal surgery or vasectomy reversal).

Miscarriage A naturally occurring spontaneous abortion or loss of a baby before 20 weeks gestation.

Multifoetal pregnancy reduction Reduction of multiple foetuses or babies in the uterus, because of risk of extreme premature delivery or miscarriage.

Multiple pregnancy Where two or more foetuses develop in pregnancy. Much more common after ovarian stimulation, including in IVF (15.1% twin rate and 1.6% triplet rate in 1995 cited in Assisted Conception, 1997). Increased risk of miscarriage, early delivery, and stillbirth, neo-natal death and a range of physical and developmental problems in the premature infant. In 1994, 56.8% of 81 perinatal deaths after IVF occurred in multiple births (Assisted Conception, 1997:1).

National Ethics Committee on Assisted Human Reproduction (NECAHR) Set up in 1995 to review new ART proposals, develop protocols and guidelines and advise the New Zealand government on ART issues.

Oligozoospermia Poor sperm count, i.e. less than 20 million sperm per ml.

OHS See Ovarian Hyperstimulation Syndrome.

Open Adoption Adoption in which information is exchanged between birth parents and adoptive parents.

Oocyte Also known as an egg or ovum; the female reproductive cell, produced in the ovaries each month.

Ovarian hyperstimulation syndrome OHS is a potentially life threatening condition from ovulation stimulating drugs, marked by enlargement of the ovaries, fluid retention and weight gain. It occurs in up to 20% of women having stimulated IVF, about 1% are severely affected requiring hospitalisation. Two or three deaths from hyperstimulation have been recorded internationally.

Ovary The sexual glands of the female, which produces the hormones oestrogen and progesterone, in which egg follicles are developed.

Ovulation The release of a mature egg from the ovary, usually in the midpoint of the menstrual cycle.

Ovulation induction Administration of ovulation medications to stimulate the ovaries to ovulate.

PCOS See Polycystic Ovarian Syndrome.

Pelvic inflammatory disease Infection in the uterus, fallopian tubes and ovary that may cause pain and scar tissue formation (adhesions) and tubal infertility.

PID See pelvic inflammatory disease.

Polycystic ovarian syndrome PCOS occurs when multiple small cysts develop because of arrested follicular growth and enlarge the ovaries. Symptoms may include: irregular menstruation, obesity and infertility.

Preimplantation genetic diagnosis Screening of embryos for genetic disorders before implantation involving IVF, embryo biopsy and molecular genetic testing.

Premature ovarian failure Early menopause, where menstruation ceases due to failure of the ovaries before the age of 40.

Primary infertility Infertility where the woman or couple have not had a pregnancy before.

Recipient Woman or couple who receive donor gametes, either sperm or eggs from a donor, who can be anonymous or known to them.

Reproductive technology Technology used to assist conception, which separates reproduction from sexual intercourse.

RTAC Reproductive Technology Accreditation Committee, which accredits fertility centres in New Zealand and Australia.

Secondary infertility Infertility where there has been a child born to the woman or couple (sometimes refers to where there has been a previous pregnancy).

Semen The fluid containing sperm released during male ejaculation.

Semen analysis Microscopic examination of semen to determine number of sperm (sperm count), shapes (morphology) and ability to move (motility).

Sexually transmitted disease STD's are infections transmitted by sexual contact e.g. gonorrhoea, herpes, human wart virus, chlamydia and AIDS. They can cause infertility in both men and women.

Sperm The male reproductive cell.

Sperm antibodies The presence of sperm antibodies in the woman or man that can destroy sperm action by immobilising or clumping them.

Sperm count Number of sperm per millilitre of semen. A normal count is usually 20 million or more per millilitre.

Sperm morphology The form, structure and shape of sperm. At least 50% of sperm should have normal shape.

Sperm motility Percentage of all moving sperm in a semen sample. Normally 50% or more are moving rapidly.

Spontaneous pregnancy Pregnancy conceived naturally, rather than with medical assistance.

STD See Sexually Transmitted Disease.

Subcutaneous injection Fine injection under the skin.

Surrogacy Reproductive arrangement where a surrogate woman is inseminated by sperm from the man of the commissioning couple. She is genetically related to the child, though has agreed to relinquish child. See Gestational Carrier.

Testicle The male sexual glands (testes) contained in the scrotum, which produce sperm and the hormone testosterone.

Testicular biopsy Small surgical excision of testicular tissue to determine the ability of cells to produce normal sperm.

Testicular sperm aspiration TESA to surgically remove sperm directly from the testes, to use with ICSI, avoiding need for ejaculation.

Transvaginal ultrasound Ultrasound imaging technique using vaginal probe to view woman's organs and eggs on a monitor screen, with IVF.

Tubal ligation Sterilisation of female to prevent conception, by clipping or tying fallopian tubes.

Ultrasound Scanning procedure using high frequency sound waves to monitor growth of ovarian follicles, pregnancy and retrieve eggs from ovaries, in case of IVF.

Uterus Woman's womb, where pregnancy grows.

Vagina The canal in the woman that leads to the cervix, opening to the uterus.

Vasectomy Sterilisation of male to prevent conception.

Vasectomy reversal Operation to try to reconnect the vas, restoring male fertility.

Whakapapa Maori term to describe the centrality of genealogy to Maori identity, continuity and belonging to the land, by awareness of one's ancestors, tribal (iwi) and extended family (whanau) connections.

WHO World Health Organisation

Appendix 2: Preliminary study consent form

14 Reserve Terrace
Lyttelton
Christchurch
Phone 328-7420

Dear

I am writing to ask whether you would participate in a small study I am undertaking for a PhD through the Social Policy and Social Work Department at Massey University. The New Zealand Infertility Society supports the study.

The pilot study is a retrospective one with about six couples in the Christchurch area who have experienced infertility and who are moving on from that in variety of different ways. I am interested to understand the processes of decision-making that people use when faced with infertility and the reasons why people make the choices they do. As a social worker, I am also interested in the most useful and appropriate role of counsellors in the area.

The study would involve a taped interview of about one and a half hours in a guided discussion format. Responses will be anonymous, with participants choosing a name to be called. The tapes and transcripts can be returned if wished, or destroyed. A draft will be made available to ensure its accuracy and confidentiality. The results of the study will be given to respondents. Participation in the study can be withdrawn at any stage for any reason.

It is important that the report drawn up from the analysis of results accurately reflects the range of perspectives and experiences that people have. This includes hearing male voices on issues where there has been silence.

I would really appreciate your participation in the research, but respect what you decide.

Yours sincerely

Anna Thorpe

Appendix 3: Preliminary study consent form

CLIMBING OFF THE INFERTILITY TREADMILL

How people stop infertility treatment and move on

CONSENT FORM

Pilot Study by Anna Thorpe
14 Reserve Terrace,
Lyttelton,
Christchurch,
Phone 328-7420

Thank you for agreeing to participate in a small study being conducted by Anna Thorpe, a PhD student with the Social Policy and Social Work Department at Massey University.

The purpose of this study is to identify the different ways infertile people move on from infertility treatment.

As participants, we understand that we can withdraw from the study for any reason and at any time.

Our participation will involve a guided interview, about one and a half hours long.

We understand that all reasonable measures to ensure confidentiality of our records will be taken. If we wish, we can have the tape and original transcripts of the tape returned to us once the research is complete. Otherwise they will be destroyed. We will be given a summary of the results of the interviews.

We understand that this is not a counselling session, and if active issues arise during the interview, that a referral elsewhere will be suggested.

We have read this consent form and have had the opportunity for discussion. We consent to participate in this study identifying the different ways people move on from infertility treatment.

Date ____________________

Participant's Signature ____

Participant's Signature ____

Interviewer's Signature ____

Appendix 4: Preliminary study questionnaire

CLIMBING OFF THE INFERTILITY TREATMENT TREADMILL: HOW PEOPLE STOP TREATMENT AND MOVE ON

Pilot Questionnaire by Anna Thorpe

Given male name:
Given female name:

Description (written)

1. What is your age

Male	Female
< 24	< 24
25 - 29	25 - 29
30 - 34	30 - 34
35 - 39	35 - 39
40 - 44	40 - 44
45 >	45 >

2. What ethnicity are you

Male	Female
European/Pakeha	European/Pakeha
Maori	Maori
Pacific Island	Pacific Island
Asian	Asian
Other	Other

3. In which partner is the medical cause of infertility
   male
   female
   male/female
   unexplained

4. How many years passed before seeking medical assistance for infertility
   < 1
   2 - 3
   4 - 5
   6 <

5. How many years have you had infertility work-up and treatment for
   < 2
   3 - 5
   6 - 10
   11 - 14
   15 <

6. What infertility treatments have you tried
   none
   surgery

drug therapy
Donor Insemination (DI)
Intra-Uterine Insemination (IUI)
In Vitro Fertilisation (IVF)
other ____________________

7. How many children do you have, if any

8. Means of having these children
   spontaneous
   drug therapy
   DI
   IUI
   IVF
   adoption/guardianship
   other ____________

9. How much have you spent on infertility work-up and treatment (approx.)
   > $1,000
   $1,000 - $5,000
   $5,000 - $10,000
   $10,000 - $15,000
   $15,000 - $20,000
   $20,000 - $25,000
   $25,000 - $30,000
   $30,000 <
   refused

Effects of Infertility (taped)

10. How important was being a parent to your sense of self as you became an adult

11. What impact has infertility had on your hopes and plans

12. What impact has infertility had on your relationship

13. How do you interact in a world where most people are fertile
    -how open are you and have you been about your infertility
    -how has it changed the social choices you make

14. Have you noticed any differences in the way that you cope with infertility now, compared with previous years

Treatment Choices

15. Why and how did you decide to start infertility treatment

16. Did one person more than the other initiate and sustain the motivation to keep 'trying'

17. How have each of your cultural backgrounds influenced the choices you have made

18. What treatments wouldn't you have tried at the onset of your infertility

19. Were you aware of any limits you had when pursuing treatment
    E.g. length of time on a fertility programme, age, and money spent

20. Did these limits change over time, and why

21. What contact over the duration of your infertility did you have with counsellors, and for what reason

22. If you did have infertility counselling,
    -what did you perceive the role of the counsellor to be
    -what was valuable in the process
    -what else was needed from a counsellor, and at what stage

22. If no counselling regarding infertility was available or sought, what would have been useful and at what stage

23. Why and how did you decide to stop treatment

24. Was one person more than the other responsible for this decision to stop 'trying'

25. How do you make decisions in other areas of your lives together and is this process similar to infertility-related decisions

Moving On

26. How do you gradually accept and adjust to infertility

27. Were there any significant events that acted as turning points in your decision to 'move on"

28. Do you know people who do not have children, whose lives are satisfying and meaningful

29. Have you built children into your lives

30. How have you made sense of your infertility, philosophically and spiritually

31. What have you learned from your infertility journey

32. What would you say your purpose in life is now
    -how satisfying is this

33. What visions for your future do you have

Appendix 5: Letter inviting participation in main study

Christchurch Women's Hospital
Private Bag 4711
Christchurch

Dear

I am writing to ask whether you would be able to participate in a study that our unit is involved with.

The study is randomly targeting couples in the *in vitro* fertilisation and donor insemination programmes at Christchurch Women's Hospital, who have had several cycles of treatment. The study is interested in the different ways people make decisions about treatment, particularly in terms of understanding how people move on from infertility treatment. Results will contribute towards a greater understanding of the experiences and needs of people moving through infertility programmes.

Anna Thorpe, the counsellor with our IVF programme is undertaking the research as part of her PhD with Massey University. Approval for the study has been granted by the Ethics Committees of the Southern Regional Health Authority and from Massey University. The IVF and DI Units at Christchurch Women's Hospital support the study, as does the New Zealand Infertility Society.

Participation in the study will involve two interviews as a couple, either in your home or at Christchurch Women's Hospital. Participation will be strictly confidential and may be withdrawn at any time. Your future treatment with the Unit will not be affected whether you choose to participate or not.

I enclose an information sheet and personally encourage your participation in the study. We hope to hear from you soon and provide a reply form and stamped envelope for your convenience.

Yours sincerely

Peter Benny
Medical Director

Appendix 6: Main study information sheet

INFERTILITY TREATMENT DECISIONS

STUDY INFORMATION SHEET

Research Aims:

The study aims to identify the different reasons that people have for stopping donor insemination (DI) or *in vitro* Fertilisation (IVF) treatment. In 1994, couples toward the end of their available treatment cycles on the DI and IVF programmes at Christchurch Women's Hospital, will be interviewed twice over the year. This is to identify any changes that may have occurred with the couple's situation, decisions and treatment limits over time. The survey is also interested in the most useful counsellor role for dealing with infertility issues.

Research Involvement:

In explaining the study, an invitation is extended to the couple to participate, subject to the couples consent. Participation in the study involves two interviews as a couple. These interviews will be held about nine months apart and will take about one hour each. Part of the interview will involve answering a questionnaire, the other part will involve a taped discussion. Confidentiality will be protected and a summary of results provided to participants.

Participants have free access to the Social Work and Counselling Service at Christchurch Women's Hospital and the Patients Advocacy Service.

The Researcher:

Anna Thorpe, the counsellor with the IVF Unit at Christchurch Women's Hospital, is undertaking the research as part of a PhD through the Social Policy and Social Work Department at Massey University. The IVF and DI Units at Christchurch Women's Hospital and the New Zealand Infertility Society support the study.

Contact:

For more information, please contact: Anna Thorpe
IVF Unit
Christchurch Women's Hospital
Private Bag 4711
Christchurch
Ph.(03)364-4549 or (03)364-4856

Appendix 7: Main study reply form

Study Reply Form

Tick here _______ We would be interested in Anna Thorpe contacting us about the Infertility Treatment Decisions Study.

Tick here _______We are not interested in participating in the Infertility Treatment Decisions Study.

Names:

Address:

Phone:

Appendix 8: Main study consent form

INFERTILITY TREATMENT DECISIONS STUDY

CONSENT FORM

Researcher: Anna Thorpe
IVF Unit
Christchurch Women's Hospital
Private Bag 4711
Christchurch
Phone (03)364-4821 or (03)364-4856

We understand that our participation in this study will involve two interviews, about nine months apart and one hour long. This interview involves a questionnaire and a guided discussion that is taped.

We understand that all reasonable measures to ensure confidentiality of our records will be taken. We will be given a summary of the results of the study.

We understand that we can withdraw from the study for any reason and at any time without adversely affecting our future care. We also understand that we are able to ask any question whatsoever regarding the process and background of this study.

We understand that the procedures have been approved by the Southern Regional Health Authority Ethics Committee (Canterbury) and the Massey University Ethics Committee.

We have read this consent form and the information sheet prepared for the study and have had the opportunity for discussion. We consent to participate in this study identifying the different ways people move on from infertility treatment.

Participant's Signature: ________________________ Date: ____________

Participant's Signature: ________________________ Date: ____________

Researcher's Signature: ________________________ Date: ____________

Appendix 9: Main study questionnaire 1

INFERTILITY TREATMENT DECISIONS

Questionnaire One by Anna Thorpe

Male Name:
Female Name:
Address:

Phone:
Date:

Assumed male name:	Subject number:
Assumed female name:	Subject number:

Description:

What age are both of you

Male	Female

What ethnicity are you

Male	Female
European/Pakeha	European/Pakeha
Maori	Maori
Pacific Island	Pacific Island
Asian	Asian
Other___________	Other___________

3. What is your current source of income

Male	Female
wages / salary	wages / salary
benefit	benefit
student allowance	student allowance
self-employed	self-employed
partner's salary	partner's salary

4. For about how many years have you not used contraception

5. How many years ago was infertility first diagnosed

6. In which partner is the medical cause of infertility
   - male
   - female
   - male / female
   - unexplained

7. Have you had a pregnancy before, either together or with another partner

Together	Male	Female
yes	yes	yes
no	no	no

8. How many children do you have, if any (if none, go to question 10)

	Together	Male	Female

9. Means of having children	Together	Male	Female
spontaneous			
surgery			
drug therapy			
Donor Insemination (DI)			
Intra-Uterine Insemination (AIH)			
In Vitro Fertilisation (IVF)			
adoption / guardianship			
other__________________			

10. What infertility treatments have you tried (*current treatment)
surgery
drug therapy
DI
AIH
IVF/GIFT
natural healing methods
other________________________

11. How many months or times have you tried each of these (approx)
surgery
drug therapy
DI
AIH
IVF/GIFT
natural healing methods
other________________________

12. What have you spent on infertility visits, tests & treatment (approx)
0 - $2,000
$2,000 - $5,000
$5,000 - $9,000
$9,000 - $13,000
$13,000 - $17,000
$17,000 - $21,000
$21,000 - $25,000
$25,000 - $30,000
$30,000 +
refused

Treatment Choices:

13. Did you make a conscious decision to start infertility treatment

	Male	Female
no		
yes		

14. Did one person more than the other initiate and sustain the motivation to keep 'trying' to have a child

Male Female

no both
yes female
male

15. When infertility was first diagnosed, what treatments would you have hesitated to try

Male Female

Nothing
donor sperm
IVF
other__________________

16. In what way have your values and beliefs influenced the treatment choices that you have made

Male Female

no influence
wouldn't use donor sperm
wouldn't discard embryos
other__________________

17. Were you aware of any limits or constraints during treatment

Male Female

length of time on treatment
age
cost of treatment
number of cycles
emotional strain
other___________________

18. Have these limits changed over time

Male Female

no
yes length of time
age
cost
number of cycles
emotional strain
other____________

19. Did you have any breaks longer than one year from treatment
no
yes If so, why___________________________________

20. What might stop you having further treatment

Male Female

medical recommendation
treatment unavailability or limits
emotional strain
menopause

when have children
lack of money
acceptance of situation
partner's decision to stop treatment
don't know
other________________________

21. What information do you need to make the decision to stop treatment

Male Female

medical chance of success
options for the future
other_____________________

22. Do you think it will be a conscious decision to stop treatment

Male Female

yes
no
medical limit
don't know

23. Do you think that one person more than the other will be responsible for this decision to stop 'trying' for a pregnancy

Male Female

no both
yes female
male

24. Who tends to take responsibility for making important decisions in other areas of your lives e.g. managing the budget

Male Female

female partner
male partner
both

Living With Infertility:

25. Have you noticed any changes in the way that you cope with infertility over time

Male Female

no similar
yes cope better
cope worse
coping varies

26(a) If childless
How have you built children into your lives

Male Female

relationship with other's children
fostering
haven't
other______________________

26(b) If parents

Given that you are now parents, do you think it will be easier to stop having further treatment, if it is not successful

	Male	Female
yes		
no		
don't know		

27. How do you describe yourselves to others

	Male	Female
infertile		
childless		
sterile		
childfree		
parent		
don't have children		
other______________________		

28. Do you know infertile people who do not have children, whose lives you would describe as satisfying and meaningful

	Male	Female
no		
yes		
don't know any infertile people		

29. What level of personal support do you have outside your relationship with your infertility

	Male	Female
a lot		
some		
none		

30. Have you attended or contacted an infertility support group on more than one occasion in the last two years

	Male	Female
no		
yes		

Counselling:

31. How many counselling sessions have you had around infertility issues

	Together	Male	Female
0 (if none, go to question 39)			
1			
2 - 4			
5 – 7			
8 -10			
11+ sessions			

32. When did you last have contact with a counsellor on infertility issues

	Together	Male	Female
within 6 months			
within 1 year			
within 18 months			
within 2 years			
more than 2 years ago			

33. How did you have contact with counsellors over the duration of your infertility

	Together	Male	Female
IVF			
DI			
Self-initiated			
referred for associated problems			

34. Were you clear about the role of the counsellor

	Male	Female
no		
yes		

35. What do you think the *role* of the counsellor was (use flashcard)

	Male	Female
compulsory part of treatment		
assessment		
being known if needed in future		
information giving		
assistance with decision-making		
support		
dealing with relationship issues		
stress management		
coping with infertility strain		
coping with treatment		
coping when treatment fails		
dealing with depression		
anger management		
controlling anxiety		
coping with pregnancy loss or stillbirth		
parenting after infertility		
ways to move on from treatment		
clarifying options for the future		
all of the above		
other____________________________		

36. What aspects of counselling were *helpful* (flashcard)

	Male	Female
feeling understood		
being known if needed in future		
information giving		
assistance with decision-making		
support		
dealing with relationship issues		

stress management
coping with infertility strain
coping with treatment
coping when treatment fails
dealing with depression
anger management
controlling anxiety
coping with pregnancy loss or stillbirth
parenting after infertility
ways to move on from treatment
clarifying options for the future
other____________________________
nothing helpful

37. What was *not* helpful in counselling (flashcard)

	Male	Female
assessment		
childfree emphasis		
counsellor's approach		
asked too many personal questions		
other_________________________________		
nothing helpful		
all helpful		

38. Did the counselling you received as part of a fertility programme influence your feelings or thoughts about having the treatment

		Male	Female
no			
yes	second thoughts		
	motivated		
	other_________________________		

39. Did counselling you had help address the decisions about:

	Male	Female
what treatments to have		
when to begin treatment		
how long to continue treatment		
stopping treatment		

40. What *would* have been helpful from counselling (flashcard)

	Male	Female
information giving		
assistance with decision-making		
support		
dealing with relationship issues		
stress management		
coping with infertility strain		
coping during treatment		
coping when treatment fails		
dealing with depression		
anger management		
controlling anxiety		

coping with pregnancy loss or stillbirth
parenting after infertility
ways to move on from treatment
linking with community support
other__________________________

41. At what stage would counselling have been valuable

	Male	Female
when infertility was first diagnosed		
after failed treatment		
after treatment options had run out		
other________________________		

42. Should follow-up counselling be offered after a certain amount of time on an infertility programme

	Male	Female
no		
yes if so, when_______________		

43. Do you think counselling should be an optional or compulsory part of treatment

	Male	Female
optional		
compulsory		

44. Would you have gone to counselling if it was optional

	Male	Female
yes		
no		

Open Questions (Taped):

1. How have you learned to live with infertility

2. How have you changed from your infertility experiences

3 (a) If childless
How do think having children one way or another would affect your lives

3 (b) If parents
What do think your lives would change if you didn't have children

4. How have you made sense of your infertility, in a philosophical or spiritual way

5. What would you say your purpose in life is now - how satisfying is this

6. What other comments would you like to make before we finish

Appendix 10: Main study questionnaire 2

INFERTILITY TREATMENT DECISIONS

Questionnaire Two by Anna Thorpe

Male Name:
Female Name:
Address:
Phone:
Date:

Assumed male name:	Subject number:
Assumed female name:	Subject number:

Description:

Since the last interview in 1994, what factors have changed, if any:

1. Have you had any (more) children
   - no (go to question 3)
   - yes
   - pregnant

2. If yes, through what means did you have these recent children
   - spontaneous
   - surgery
   - drug therapy
   - donor insemination (DI)
   - intra-uterine insemination (IUI)
   - in vitro fertilisation (IVF)
   - adoption/guardianship
   - other______________________

3. What infertility treatments have you tried since then (*current)
   - none
   - surgery
   - drug therapy
   - DI
   - IUI
   - IVF
   - natural healing methods
   - other_______________

4. How many months or times have you tried these treatments since the last interview
   - surgery
   - drug therapy
   - DI
   - IUI
   - IVF

natural healing methods
other_______________

5. What have you since spent on infertility visits, tests and treatment (approx)

none
- $999
$1,000 - $1,999
$2,000 - $2,999
$3,000 - $3,999
$4,000 - $4,999
$5,000 - $5,999
$6,000 + (specify)
refused

Treatment Choices:

6. Have you finished infertility treatment Male Female

yes
no (go to question 10)
don't know (go to question 10)

7. What were your reasons for stopping treatment

Male Female

medical recommendation
treatment unavailability
age
had children
lack of money
acceptance of not having children
partner's decision to stop treatment
do not know
other_____________________________

8. Was one person more than the other responsible for this decision to stop treatment

Male Female

no both
yes female
male

9. People who have stopped treatment talk about having a number of responses. Do any of the following apply to you

Male Female

relieved
able to focus on other things
right timing
reluctantly stopped
other___________________________

(go to question 18)

10. Has one person more than the other sustained the motivation to keep going through treatment

		Male	Female
no	both		
yes	female		
	male		

11. Are you aware of any limits or constraints you personally have regarding stopping treatment

	Male	Female
length of time on treatment		
age		
cost of treatment		
number of cycles		
emotional strain		
other___________________		

12. Have these limits changed over time

		Male	Female
no			
yes	length of time on treatment		
	age		
	cost of treatment		
	number of cycles		
	emotional strain		
	other___________________		

13. What might stop you having further infertility treatment

	Male	Female
medical recommendation		
treatment unavailability		
age		
when have got children		
lack of money		
acceptance of not having children		
partner's decision to stop treatment		
don't know		
other_________________________		

14. Do you think it will be a conscious decision to stop treatment

	Male	Female
no		
yes		
medical limit		
do not know		

15. Do you think that one of you more than the other will be responsible for this decision to stop 'trying' for a pregnancy

		Male	Female
no	both		
yes	female		
	male		

16. Do you think you will feel ready at some point in time to stop treatment, if you haven't had a child

	Male	Female
no		
yes		

17. Regardless of the outcome of treatment, when it ends, do you think you will experience any of the following

	Male	Female
freedom from uncertainty		
wanting to get on with other things		
needing to accept the situation		
ability to plan life more effectively		
having greater control over life		
feeling high personal strain		
worry/concern about the future		
can't imagine being ready to stop		
other________________________		

18. How much control do you feel you have (had) over your infertility treatment

	Male	Female
total control		
a lot		
some		
no control		

Living with infertility:

19. Have you noticed any changes in the way that you have coped with infertility over the last year

		Male	Female
no	similar		
yes	cope better		
	cope worse		
	coping varies		

20 (a) If childless, have you built children into your lives

		Male	Female
no	have not		
yes	special relationship with nephews/nieces		
	fostering		
	other______________________________		

20 (b) If parents, do you think it will be easier to stop having further treatment, if it is not successful

	Male	Female
no		
yes		
do not know		

21.How important a goal was being a parent as you were growing up

	Male	Female
very important		
important		
quite important		
not important		

22. Do you think that women are more fulfilled if they are mothers

	Male	Female
no		
yes		

23. Do you think that men are more fulfilled if they are fathers

	Male	Female
no		
yes		

24. Do you feel your experiences of infertility make you any different from others

	Male	Female
no		
yes		

why______________________________

____

25. How do you 'think' of yourself, in terms of infertility

	Male	Female
infertile		
childless		
sterile		
childfree		
fertile		
parent		
don't have children		
can't have children		
avoid answering		

26. Do you think it would be possible for you to have a satisfying and meaningful life, without children

	Male	Female
no		
yes		

why______________________________

____

27. How public or private are you about infertility

	Male	Female
completely open		
tell close friends/family		
tell other infertile people		
very private		

28. What are your reasons for being open (or not) with your infertility

	Male	Female
support		
share important aspect of life		
open person		
private person		
own business		
people don't understand		
other________________________		
________________________		

29. What are your expectations of support from other people with your infertility

	Male	Female
a lot		
some		
none		

30. Have you contacted an infertility support group in the last year

	Male	Female
no		
yes		

Counselling:

31. Since our last interview, have you had any contact with counsellors

		Male	Female
no	(go to question 36)		
yes	IVF		
	DI		
	other____________________		

32. Since our last interview, how many counselling sessions have you had around infertility issues

	Male	Female
0		
1		
2 - 4		
5 - 7		
8 +		

33. Was your decision to seek counselling influenced in any way by our first interview

	Male	Female
no		
yes		
not sure		

why________________________

34. What were your reasons for having the counselling

	Male	Female
information		
decision-making		
support		
relationship issues		
stress management		
infertility strain		
treatment strain		
treatment failure		
depression		
anger		
anxiety		
coping with pregnancy loss or stillbirth		
parenting after infertility		
moving on from treatment		
options for the future		
other____________________________		

35. What aspects or focuses of recent counselling were valuable

	Male	Female
information		
decision-making		
support		
relationship issues		
stress management		
infertility strain		
coping during treatment		
coping with failure		
depression		
anger		
anxiety		
coping with pregnancy loss or stillbirth		
parenting after infertility		
moving on from treatment		
options for the future		
other____________________________		
nothing		

36. Has the counselling made any difference in your thoughts about continuing or stopping treatment

	Male	Female
no		
yes		
why____________________________		

37. Do you think having counselling changed the amount of support you sought from others regarding the infertility

	Male	Female
no		
yes		
why____________________________		

38. Would it have made any difference if you knew the counsellor had personally experienced infertility

		Male	Female
no	none		
yes	some		
	a lot		
	why________________________		

Open Questions (Taped):

1. Since the last interview, what thoughts have you had about your infertility experience

2. What, if any, have been the positive aspects of your experience with infertility

3. What, if any, have been the negative aspects of your experience with infertility

4 (a) If childless
How has your experience of infertility and childlessness influenced your identity, both in terms of how you see yourself and how others see you

4 (b) If parents
How has your experience of infertility and being a parent influenced your identity, both in terms of how you see yourself and how others see you

5. What would you say now to someone you knew, who seemed very focused on trying to have a child and who wanted to continue having infertility treatment indefinitely

6. What are the key ingredients to making "the right" decisions about infertility treatment for you

7. What would you say your purpose in life is now
-how satisfying is this

8 (a) If childless
How will you adapt your purposes in life if you remain childless

8 (b) If parents
Since you have had children, have your purposes in life changed at all, and how

9. What other comments would you like to make before we finish

Appendix 11: Main study questionnaire 3

INFERTILITY TREATMENT DECISIONS

Questionnaire Three (by telephone)

Male Name:
Female Name:
Address:
Phone: *check, plans to move?*
Date:

Assumed male name: Subject number:
Assumed female name: Subject number:

1. Since the last interview in 1995, what factors have changed, if any:

2. Have you had any (more) children

3. If yes, through what means did you have these recent children

4. Were you expecting to have any treatments in the last 18 months

5. Have you made a decision about having further treatment (stopped/active/non-active/in limbo)
Go to Q.10, if stopped and no further treatment

6. What infertility treatments have you tried since then

7. How many times have you tried these treatments since our last meeting

8. How much have you spent on treatment since then (approx)

9. What treatment do you have planned for the future

10. Do you have a time frame for these treatments

11.Are there any further comments you would like to make

A summary of findings will be sent to you later.

Appendix 12: Follow-up letter to participants

14 Reserve Terrace
Lyttelton 8012.
Ph. 328-7420

17 February 2004

Dear

I am writing to send you a final summary of the study that you participated in from 1995-1998, called 'Negotiating Infertility Treatment Decisions'. I apologise for its delay. My life was interrupted by the very premature births of two sons in 1998 and 1999, which involved a lot of hospitalisation for all three of us. Their wonderful, but stressful, arrival meant I needed to abandon my study until 2003, when I resumed writing up as a Master of Social Work.

The results have great potential to assist in the understanding of the process of decision-making among those facing infertility treatment and those providing infertility services. I will firstly distribute the results to fertilityNZ and the Australia New Zealand Infertility Counsellors Association. I am also looking at where to publish particular results. If you are interested in reading a fuller account of the results or in having copies of your interview transcripts returned, please let me know. The thesis will also be lodged at the Massey University library, where it will be available through any public library using inter-library loan.

Thank you so much for your involvement. As a group of forty people, you told your own stories of negotiating infertility treatment decisions, which involved risk, trust, tears, and laughter - as we discussed an area many would feel more comfortable leaving behind. You were incredibly articulate about your infertility experiences. It was very moving and a real privilege interviewing you. This thesis would not have been possible without your time, support, insight and reflection. Thank you from the heart.

Anna Thorpe

Appendix 13: Summary to participants

Negotiating Infertility Treatment Decisions

by Anna Thorpe

The research aimed to highlight how people make infertility treatment decisions, from the time that infertility is first diagnosed, through the complex maze of treatments available, until a decision to stop treatment is made, either with or without children. The decisions required along the infertility treatment path are dazzling in their breadth, detailed in their technicality, physically daunting, emotionally demanding and ethically stretching. However, infertility decision-making processes and influences are not generally understood by those experiencing infertility and by treatment providers.

The sample of the main study targeted people who had undergone at least three donor insemination (DI) cycles or at least two *in vitro* fertilisation (IVF) cycles through Christchurch fertility clinics. The intention of targeting respondents who had undergone a moderate to higher number of treatment cycles was to learn from their longer experience of infertility treatment. The main study was designed to be longitudinal, to take several snapshots of participants' lives and decisions, in order to track their decisions, treatment statuses and family situations. From 1994 until 1997, three interviews took place with twenty couples - ten from DI and ten from IVF. A great picture unfolded of these forty peoples' lives over that time.

> "Being fertile, or being able to have children naturally hasn't been the norm... You see the instances of infertility popping up all around you. It's like when you buy a white car, you notice all the other white cars. It's looking for the norms, in those 'un-norms' around you and it's just amazing the instances of it." *Nicholas*

Participant couples had experienced infertility for an average of seven years. DI couples had tried an average number of 15 DI cycles, ranging from three to right up to thirty cycles. Three of those DI couples then tried up to nine IVF cycles (usually with donor sperm, but also with the man's sperm using ICSI). In comparison, IVF couples had an average of five IVF cycles, between two and eleven. Almost half the participants had undergone surgery for infertility. They had spent an average of $9,000 for DI couples and $11,000 for IVF on infertility tests and treatment. Two thirds of couples ended up with children through treatment, adoption or naturally. One third had none. Two families were blended - naturally conceived children together with siblings from DI or adoption. Two women had adopted out children when they were younger. Two men were infertile after treatment for cancer. Three people had children to former partners. Two men had undergone vasectomies and needed DI after unsuccessful reversals. Half the couples had experienced loss of pregnancy, up to four times. One couple separated during the study.

Key findings and their implications

This study uncovered a number of significant results. Because of its longitudinal nature over two and a half years, it was possible to track the status and movement of people's infertility treatment. Information gathered from three time snapshots allowed for the development of an original model of treatment status. This model showed that people fell into four main treatment groupings: 'active' for those having active treatment; 'non-active' for those having a break between cycles, with the intention of resuming treatment; 'in limbo' for those uncertain about whether to resume treatment or quit altogether; and 'stopped' for those who had clearly ended their treatment and moved on, either with or without children. There was considerable movement between these different treatment statuses, depending on opportunity and readiness. People were found to generally move from being active in treatment, through non-active or in limbo periods, towards stopping treatment. The model allows for the nature and movement of people's infertility treatment to be better recognised and understood by those having or contemplating infertility treatment, and those who are involved in providing infertility services. This woman stopped treatment, but then wanted to try intracytoplasmic sperm injection (ICSI), which had just become available.

> "Having made the decision that we were more-or-less happy with not having children, now that this other possibility has come up. We're almost back where we

> started, just trying to decide whether we should look at going ahead trying to have more DI - whether it's just going to put us on the roundabout again, or whether if we don't try it, it's going to nag at us for the rest of our life." *Sophia*

It was found by analysing participant's treatment status over time that breaks between treatment cycles and uncertainty about continuing or stopping treatment were relatively common among about half of the participant couples during the two and a half year research period. However, particularly being in limbo is under-recognised professionally and in the literature. People who are undecided about resuming or stopping treatment are unlikely to realise how common it is. In addition, those paralysed by decision-limbo may not know how to get through the impasse, reach agreement, or where to seek support, described here.

> "Until there's that finality, there is still hope... But there is also the limbo and that is also hard on us. We don't know where we're going." *Charlotte*

The study found obvious and predictable gender differences in the motivation to start, continue and stop infertility treatment. The more surprising influences were the differences between parents and childless respondents. Women tended to make these decisions if they were in a childless relationship, while parents made these decisions more jointly. The main limits to further treatment were found to be emotional strain, age and cost - which got extended by time and failure. But some people perceived no limits for themselves, as they persisted with treatment. While rarely do both partners share the same emotional reactions about continuing or stopping infertility treatment, the challenge remains for men and women to understand each other in the experience of infertility - in facing the myriad of demands and decisions together.

> "It's got to be Jane's decision, because with IVF, she's the major player. She's the one that's got to go through all the pain and discomfort for it. I don't have to. All I've got to do is the odd injection and drive her around a bit and hold her hand." *Bill*

'Anticipated decision regret' was found to motivate people to start and continue infertility treatment. Many participants expressly made decisions to avoid later regretting not having taken a certain option. This generally led people to extend their treatment limits over time, particularly emotional strain, age, and money spent, until they felt satisfied with their individual 'best effort'. If successful in having a child, the extra effort would be well worth it and if unsuccessful, people are more likely to feel satisfied with their effort of trying, aiding resolution.

> "The way I felt about this last cycle - I dreaded it. I didn't want to do it and yet I knew I had to because it was the final one and if I hadn't done it, I would always wonder 'what if?'" *Jade*

'Perseverance' was found to be a common feature of those continuing infertility treatment. Many respondents suggested that people persist with treatment until they personally feel they have enough children or have had enough treatment. It was also recommended that people avoid becoming obsessive in their quest for children, which could damage the relationship or other aspects of life - instead accepting that they have to stop sometime. Persevering with treatment should be put within realistic bounds, including: what is medically warranted; what treatment can be afforded; how much stress and failure can be coped with; whether one partner in the relationship is having second thoughts about continuing; and side effects on health. Treatment cannot be continued indefinitely, and knowing when to stop is a key ingredient in healthy decision-making.

> "I'm still wanting to go and go and go. And it will always be in the back of my mind that yes I do want to try and still push myself a bit more. They'll probably literally have to stop me, because I think I'd still want to try and I suppose it will be Murray that will turn around and sort of say 'right, we're going to go off and do this', and take me away from it." *Valerie*

Stopping treatment without children is one of the most difficult decisions to be faced with infertility treatment. Exiting the medical quest for a child is likely to be emotionally difficult and prolonged. The longitudinal model of treatment status showed that stopping treatment is not always a final decision, as some participants repeated treatments or tried new options. Having children was the main reason for stopping infertility treatment by parents, followed by getting too old and not being able to afford treatment, then (for mostly men) the partner's decision to stop. Surprisingly, half the participants needed no medical information at all to make the decision to stop, while others (mainly IVF) saw medical limits imposing a stop on them. When respondents stopped treatment and moved on, they experienced, or anticipated feeling, freedom from uncertainty; being able to plan ahead; being able to get on with the rest of their life; and if childless, emotional strain and concern about their future.

> "It's the uncertainty of the whole thing... You think 'now because I have to go on the programme, well I might get pregnant'... It makes it very difficult to think and plan long-term. The last five years have been dominated by this... (Now) it's quite good, because you can look forward and plan." *Lois*

The implications of stopping infertility treatment are greatest for those who do not have children. While assisted reproduction is often offered as the solution to the problem of infertility, treatment is not perfect and many people do not become parents. However, pregnancy is not the only way to measure success after infertility treatment. Learning to live with infertility is deeply challenging, requiring time and a conscious shift from pain, sorrow and loss to a new self-concept and anticipated future. As several participants noted, facing infertility brings strength, learning, perspective, togetherness in the face of adversity and the opportunity to re-order what is important in life. The reclaiming of one's life back, after years of feeling as if it were on hold during infertility treatment, can bring relief and a sense of renewed control. Life can be rich, varied and satisfying despite the lack of children, as people put their energy into their relationships, careers, nurturing other people's children, interests or special projects.

> "The bottom line, I guess, is to be thankful for what you've got. We are all in some shape or form a statistic of something, and unfortunately ours has to be the infertility. Don't put it behind you, as a lot of people will tell you to, because it will never go away. If you get involved with groups and you can actually help someone, divert them from the path that we went down. You just hope that you can give them some words of encouragement, wisdom, hope and that all is not lost." *Martin*

The key counselling roles, specified by three quarters of participants, were assistance with coping after treatment failure; giving information; and support. Counselling input in coping during treatment; after pregnancy loss; with emotional strain; depression; and relationship issues were also highlighted by half the respondents. Men were found to value counselling's information-giving role, while women preferred help to cope with treatment, anxiety and pregnancy loss. The strongest response from participants was an overwhelming call for follow-up contact by counsellors after a certain period of time in treatment (which is not routinely practiced), as noted by this woman.

> "The only thing out of the whole thing personally that I think could have been of benefit was... ringing everyone a couple of weeks or a week after treatment (results) and saying 'hey, how do you feel? Do you want to talk about it?' Really, really important." *Sarah*

A surprise result was that participants, notably IVF, did not find counselling helpful for their infertility decision-making and moving on from treatment. This was because of the limited counselling they had and from making 'autonomous' decisions or with input from their doctor. However, half the respondents, particularly women and those having DI, wanted counselling input with their infertility decision-making. Even more, three quarters, would have appreciated counselling involvement with their future options and the process of moving on from infertility treatment. But few respondents received these elements from the counselling they had. Neither interestingly, had they sought out further counselling for these matters, even though they knew of it's availability at no cost. It is significant that participants made infertility decisions without support, considering that almost half of them had periods of limbo during the study, some of which were very prolonged.

> "You've got to help yourself, nobody else can help you. They can advise you, but you've still got to do it within, from yourself." *Dave*

Experiencing infertility with its many losses, and facing an uncertain future was found to be deeply challenging. As one man sums up,

> "I could certainly do without it." *Michael*

Appendix 14: Fertility and infertility statistics

To help uncover fertility trends, it is worth looking at the detailed data on birth and fertility rates kept by Statistics New Zealand, from four yearly censuses. While the research period of this study was the mid to late 1990's, it is also useful to compare this time frame with that from post-second world war data up until the present day. This gives a perspective over time from which to get a sense of population trends. The two most significant population trends are:

- the trend towards a lower birth rate and smaller families; and
- the trend towards women giving birth at a later age.

The lower birth rate means that just over the last ten years to 2002, live births have dropped almost 3,500 or about four percent down to 54,021. This is also reflected in a drop of the crude birth rate (number of births per 1,000 estimated mean population) from a high of 17.89 in 1990 down to 13.70 in 2002.

Women's age is a critical childbearing factor, as rates of infertility and miscarriage increase as women get older (Conway & Valentine, 1988:46). The median age of New Zealand women giving birth continues to rise steadily. In the December 2002 year the median age of women having a baby was 30.1 years, compared with 28.2 years ten years previously in 1992 and 24.9 years in the early 1970's. The most common age range for women giving birth was 30-34, closely followed by the 25-29 year age group. The fertility rate for women aged 20-24 years has decreased steadily since the 1960's while the number of mothers aged thirty and above has increased significantly in the past twenty years. The proportion of babies born to women in their thirties has increased from 21 percent in 1982 to 36 percent in 1992, and to 47 percent in 2002. At the same time the proportion of women having a child at 40 years and over has increased over the same period from 0.8 percent to 1.4 percent to 3.3 percent. Statistics New Zealand reports that "half of all newborn babies now have a mother aged thirty years or older (Births - Summary of latest trends, 2003). This necessarily means that women are more mature when making childbearing decisions (Fox, 1982).

The number of childless women is also seen to rise in New Zealand over the same time period. (Statistics New Zealand terms these women 'childfree' - which as I argue above only defines accurately those who are voluntarily childless.) By grouping women together in age groups it is difficult to get precise percentiles of childless women as the trend towards later childbearing is shown, but this also has real implications for fertility at a later age. In 1996, 15.98 percent of women between the ages of 35 to 39 had no children, dropping to 11.9 percent of 'childfree' women between forty and 44 years of age. Pakeha, or European, and Asian women across all age groups were more highly represented as having no children than women of Maori or Pacific origin. In fact in 1981, by the age of thirty, Pakeha/European and Asian women were almost twice as likely as their Maori and Pacific Island counterparts to be 'childfree'. The available information on Maori infertility is limited (Dyall, 1999:37).

Therefore, the proportion of childless women in general has risen, both from infertility and choice. The number of women who are involuntarily childless has increased, due to the increased use of birth control to delay childbearing, the more women in the paid workforce and pursuing careers (Michie & Cahn, 1997:150) and higher rates of sexually transmitted disease. Concurrently, the number of women who are voluntarily childless also increased from the 1960's with the improved status of women, improved birth control, and increased urbanisation (Cameron, 1997:205).

These two significant changing demographic trends of the lowering birth rate and delayed childbearing, plus that of suspected increasing numbers of childless women have triggered a 'cultural anxiety about maternity' (Michie & Cahn, 1997:150). This has very real implications for infertility (Pfeffer, 1993) and for decisions related to fertility treatment. It is well known that the higher the woman's age, the higher her rate of infertility. Fertility is seen to drop significantly over the age of 35, with one third of women who delay their first pregnancy until 35 years or older experiencing subsequent difficulty with conception (Rosenthal & Kingsberg, 2000:294). Infertility is more pronounced still in women over the age of forty, including the increased risk of complicated pregnancy and poorer child outcomes. Fertility clinics are treating increasing numbers of older women, as the trend towards later childbearing continues. In the year 2000, 16 percent of women seeking assisted conception were aged forty years or more, increasing 1.5 percent in a single year (Hurst & Lancaster, 2001:1). The use of donor eggs is in greater demand now as more women experience ovulatory difficulties on account of increasing age.

Appendix 15: Infertility Treatments, DI and IVF

Not all people experiencing infertility seek medical treatment (Schmidt, 1998b:63). In 1987, in the United States, only one quarter of infertile people sought treatment (Hirsch & Mosher, 1987), due not insignificantly to the private nature of infertility services there. In other countries (such as Australia), the rate of treatment can be much higher, if subsidised (Schmidt, 1998b:63). As the demand for medical assistance to have children increases, the range of new reproductive technologies also grows.

During the 1990's four major advances occurred in the area of assisted human reproduction, according to Keye (2000:29). These are the development of firstly, intracytoplasmic sperm injection (ICSI) to overcome male factor infertility; secondly, ovarian freezing, for women with ovarian cancer or ovarian failure; thirdly, economic managed care to control costs (which could pressure people into treatments they feel uneasy about morally or emotionally); and fourthly, legal and ethical aspects of reproduction. These developments and other infertility treatments, such as drug stimulation programmes; donor egg and donor embryo programmes; sperm extraction processes and ICSI in conjunction with IVF; and surrogacy are not covered in detail, except where they relate to the decision-making of the participants in this study.

Donor insemination

Donor insemination, or DI, was designed to bypass male infertility by using sperm for a donor. There are two very distinct types of users, who have very different needs and priorities, different experiences and different dilemmas (Lasker, 1998:7). Firstly, DI was initially designed for people where there are either no or very few sperm in the man's ejaculate, preventing pregnancy, or genetically inherited diseases through the male line. Included in this group are men who have had a vasectomy or unsuccessful vasectomy reversal, or who have survived spinal cord injury, chronic illness or cancer (Vercollone, 1997).

Secondly, it is an option where there is no male partner, in the case of lesbian or single women. This has become possible with the general social acceptance of single motherhood and the law change allowing single and lesbian women to gain access to fertility services. There are also a smaller number of women who practice home inseminations with semen from a known donor. DI is a relatively straightforward procedure involving the insemination of sperm obtained from a male donor into the vagina or uterus of the recipient woman in order to achieve a pregnancy.

Historically, it is very possible that alternative male sexual partners have been used for centuries to bypass suspected male sterility and DI was practiced quite widely on an informal basis during the first half of the 1800's (Pfeffer, 1993). The first known donor child was born in 1884 in the United States after an insemination secretly carried out by doctors (using a semen from one of the doctors), on a woman under anaesthesia and the first baby was reported in Nature in 1953 to have been conceived using frozen sperm (Vercollone, 1997:53). Frozen sperm is now routinely used in clinics to avoid transferring infection. DI remained a relatively quiet method of assisted conception until the 1970's and 1980's, when other reproductive technologies like IVF appeared (Daniels & Haimes, 1998:1). DI was originally known as artificial insemination by donor and has been widely offered since the early 1970's. DI has been practiced in New Zealand since at least 1945 (Daniels, 1999:6). The DI programme at Christchurch Women's Hospital first started in 1974, although some New Zealanders travelled to Australia to receive DI in those early days.

It is difficult to obtain precise New Zealand and international statistics on DI (Daniels & Haimes, 1998:2), unlike IVF. There are currently seven clinics offering DI in New Zealand. At the time of the study, pregnancy rates of the Christchurch programme were about 15 percent per DI cycle, slightly lower than natural conception rates of approximately 15 to twenty percent per menstrual cycle (McShane, 1997:20). Over ten DI cycles the pregnancy rate was 76%, with most pregnancies occurring within six treatment cycles. About 150 children are born in New Zealand from donor sperm annually (Fertility New Zealand). This is part of a much larger number of people conceived by DI internationally - conservatively estimated to be over one million in the United States alone (Haimes, 1998:54).

People on DI programmes need to wait a period of at least six months after undergoing the compulsory pre-treatment tests, counselling and medical consent interviews, to receive donor sperm, because of the shortage of sperm donors. Single and lesbian women and couples from ethnic backgrounds other than European/Pakeha face a further wait, as there is a national shortage of donors willing or with an ethnic match to donate to these recipients. Once started, people can have DI over many consecutive months, without a break. The demand for DI has decreased since the advent of ICSI, enabling men with very low sperm counts to have the possibility of a fully genetic child through micro-injection with IVF (Adair & Rogan, 1998:266). There has been a simultaneous increase in the number of single and lesbian women having DI and probably from those attracted to its significantly lower cost (in comparison to IVF).

Adding donor gametes to the family equation adds 'another rung on the treatment ladder' and involves a 'quantum leap in social and psychological complexity' (Diamond et al, 1999:14-15). These psychological complexities have precipitated careful procedures for the preparation and care of all participants in third party reproduction (Burns & Covington, 2000:20), including screening, counselling, support and education. This includes emotionally letting go of the dream of a genetically shared child.

Since its development, DI has been "shrouded in myths, misinformation and misperceptions, as well as by psychological factors including stigma, shame and secrecy" (Zoldbrod & Covington, 2000:325). The decision to use DI continues to be fraught with 'anxieties, controversies and a deep cloak of secrecy' (Lasker, 1998:7). There are particular issues to consider because there is a third party involved in the creation of a child in the form of a sperm donor, who 'gifts' his semen to assist an infertile couple or woman to conceive and passes his genetic makeup to that child. Similar issues exist in relation to egg or embryo donation and surrogacy.

Donors have initial rights of choice over who has access to their sperm, which can and does result in limitations of supply for single or lesbian women. As a cheaper and relatively successful treatment for male infertility, it is likely that DI will remain a viable choice for many (McShane, 1997:37). The consequences of DI (along with donor egg, donor embryo and surrogacy) are not merely private, but also social (Daniels & Haimes, 1998; Koch, 1999), in that they introduce change into our society by gradually introducing new concepts, practices, discourses and relationships.

In vitro fertilisation

IVF is often emotionally and physically demanding. There are many hurdles to overcome in the long journey to successfully have a child: egg development; egg collection; fertilisation; embryo development and transfer; pregnancy; and ongoing pregnancy (fertilityNZ, 2003b). A vast body of popular and research-based literature on the psychosocial impact and 'risks' of IVF has emerged since the mid 1980's (Koch, 1993). A number of side effects and possible risks are associated with IVF (The Fertility Centre, 1997), the most significant and established of which are ovarian hyperstimulation syndrome (or OHS) and multiple pregnancy, with its simultaneous risk of premature delivery (Relier, Couchard & Huon, 1993).

Louise Brown was the first baby born from IVF in England on July 28, 1978. But it was not until the mid 1980's that IVF began to be offered in many centres and in ever increasing numbers around the globe (Edwards, 1999:8). The number of IVF cycles worldwide has increased dramatically by 75 percent between 1995 and 1998 (Adamson et al, 2002:219). Based on the figures from Assisted Conception in New Zealand and Australia, 1994 and 1995 (1997), New Zealand had five IVF units and Australia 24, by 1995, contributing to 160 IVF births in New Zealand and 2,715 (or one percent of total births) in Australia in 1994. By 1999, Assisted Conception figures show that there were 421 (or 0.7 percent) births in New Zealand from IVF, compared to 4,319 (1.7 percent) IVF births in Australia (Hurst & Lancaster, 2001:1).

Success rates for IVF are complicated to pull out and analyse, because of the many variables involved. However, in 1996 during the research period, of every 100 women who started an IVF cycle at the unit (The Fertility Centre, 1997:20):

- 93 women would get as far as egg pick-up
- 85 women would have embryo transfer
- 25 women would conceive
- 19 women would have ongoing pregnancies
- 2 women would have ongoing pregnancies from thawed embryo cycles

Therefore the take-home baby rate per IVF cycle at that time (as the critical statistic for people entering the programme), was 21 percent, similar to a young fertile couple conceiving spontaneously on any given month. Even though the emphasis of clinic success rates is on the percentage of women who get pregnant (Daniluk, 2001c:104), a 21 percent take home babies per cycle necessarily meant that 79 percent are faced with failure to failure to take home a much wanted baby.

Over the past five years, there has been steady improvement in New Zealand IVF pregnancy rates (Birdsall, 2001:12). In the year up to July 2002, the take-home baby rate (as the critical rate for people entering a fertility programme, pointed out by Wiesing, 1998) for The Fertility Centre in Christchurch still stood at 21 percent per cycle started, although fewer women got to egg pick-up (to maximise the effectiveness of the very limited one publicly funded IVF cycle, which is used up by having egg pick-up). The live-birth rate increased from 19 percent in 1996 to 25 percent by 2002 for those women who got to egg pick-up. Success rates from additional frozen embryo cycles jumped to 14 percent, although this figure is complicated by multiple pregnancies and the increased likelihood of a repeat IVF pregnancy for some women with 'good' embryos. Success rates have climbed again since, standing as high as forty percent (personal correspondence, January 2004).

Overseas research indicates that the chance of taking home a baby is influenced by the number of IVF attempts. This is seen in the Australian example where the government funds up to four cycles. In New Zealand where government support is so limited, very few people would actually have the four to six cycles that optimise their chances of taking home a baby. A number of large studies have found that the cumulative pregnancy rate following IVF continues to rise over four or six cycles before it plateaus. Dor et al (1996) from Israel showed that the cumulative pregnancy rate following IVF to continue to rise to 56 percent until six cycles or until the woman turned forty. Roest et al (1998) found the cumulative pregnancy rate after three IVF cycles in Holland was 54.9 percent. Fukuda et al (2001:72) from Japan advised women under 33 years of age to have *nine* IVF cycles and those between 34 and 39 years to have seven attempts (my emphasis). Sharma et al (2002) in Britain found a cumulative pregnancy rate of 75 percent after four cycles, with 66 percent of pregnancies resulting in a live birth. These success rates dropped if women were over the age of 35 or had fewer eggs fertilised.

Appendix 16: Adoption

Adoption is an option for people faced with infertility. Adoption in this country has halved in the seven years between 1995 and 2002, to a total of 325. Non-relatives account for only 104 of those adoptions, although the number of non-relatives adopting has remained reasonably steady, decreasing by only twenty. The adoption of foreign children has also dropped during that time, by a third, to a level of 311 (Statistics New Zealand). The reasons that fewer children are placed for adoption are because of the availability of birth control and abortion; the increased prevalence and acceptability of one-parent families; the availability of limited benefits for single parents; and the emphasis on inter-family arrangements to maintain genetic and cultural links. While these social conditions are seen to have limited the availability of children for adoption, at the same time, assisted reproduction has increased the pressure to use infertility treatment (Burns & Covington, 2000:5).

Thus, while adoption remains an important way that some families are able to have children, it has gradually become less of a realistic alternative for childless couples in New Zealand. In practice, adoption is only available to married couples, although fostering is a possibility for those open to short and long–term placements without legal rights, often with children who have challenging needs. In New Zealand, adoption experiences have had a significant bearing on the donor child's right to know of their origins. Different professional opinions exist in the adoption field on the significance and time frame required to emotionally resolve infertility and stop infertility treatment, before embarking on adoption procedures (Diamond et al, 1999:168). Those who move from infertility treatment to adoption are seen to need to grieve for their many losses and resolve the issues of infertility in order to successfully move on (Salzer, 2000:408). Adoption, like medical treatment for infertility, does not offer a guarantee of parenthood. It is also usually a lengthy process involving effort, ups and downs, a changed personal identity (as adoptive, rather than birth parents), as well as bureaucratic and professional involvement.

Appendix 17: Access to Treatment in New Zealand

Prior to 1998, all DI cycles were privately funded and then cost between \$335 and \$450 per cycle. Three government funded IVF cycles (plus frozen embryo cycles) were available to heterosexual couples who had spent up to three years on a waiting list. Privately funded IVF cycles cost upward of \$3,825 during the study. Since July 1998, a complex and strict priority point system was implemented for New Zealand fertility clinics (Gillett & Peek, 1996) to rank people hopeful of receiving free treatment for infertility. These criteria cover the woman's age and ovarian reserve; length and cause of infertility; chance of pregnancy; the woman's Body Mass Index (BMI); smoking; previous sterilisations; and children from the current or past relationships. In addition, all prospective parents, including single women need to be in 'stable' circumstances for a minimum of two years (with the potential child in mind). Only women under forty years of age are government-funded, reflecting a lower success rate for women over forty. Thus, 'delayers' in the decision to have children not only have a significantly decreased chance of pregnancy, but also are not able to access free fertility treatment after the age of forty.

The cost of fertility treatment programmes has direct implications for what treatments people have, how many cycles they have and for the course of their treatment path. As of 2003 at the same Christchurch Fertility Centre, privately funded DI costs upward of \$650 per cycle, more to cover the recruitment and processing costs for known donors. IVF now costs upward of \$4000 per cycle, with additional costs of at least \$1,500 for drugs, ICSI being another \$1,500, surgical sperm biopsies and aspirations costing \$600-\$750 and donor egg being another \$2,600. User-pays IVF is a significant cost, starting at \$5,500 and extending up to almost \$8,000, which clearly limits some people's choices with treatment.

The BMI restriction has direct cultural implications for access to treatment, as 65 percent of Pacific Island women are significantly overweight (Douthett & Bennett, 1999:39). This is probably similar for Maori women (Milsom, Williamson, Gunn & Johnson, 2001). These groups also have higher rates of smoking. While fertility rates for Maori and Pacific Island women are higher than for Pakeha/ European and Asian woman in New Zealand, in terms of the number of children and the younger age of having children, Maori (and Pacific Island) women have higher rates of abortion, are more at risk of sexually transmitted disease, and have higher complications with pregnancy. These can increase the risk of infertility for both men and women (Dyall, 1999:37). These factors and the information issues of promoting fertility and accessing treatment for infertility have real implications for these vulnerable sectors of our society.

Since the priority point system was established in New Zealand clinics, couples who meet the current score of 65 are entitled free of charge to either four free DI cycles *or* to one full IVF cycle (which can also freely include a sperm extraction technique, ICSI, donor sperm, plus cycles to replace any frozen embryos the couple may have. Thus, a surprising discrepancy is uncovered, whereby significantly more public money is available to people accessing the higher costing technologies of IVF and related techniques (Winston cited by Pfeffer, 1993:170). This has meant there has been a marked increase in the number IVF cycles in which ICSI is used. In 2000, ICSI accounted for more than half (51 percent) of all embryo transfers in New Zealand and Australian IVF clinics (Hurst & Lancaster, 2001:1). Those single or lesbian women who require IVF rather than DI must pay for their own treatment, although heterosexual couples needing to use donor sperm are entitled to one free IVF. Single women and lesbian couples using donor sperm are entitled to get free treatment only if they have not become pregnant within ten privately funded DI cycles, indicating that they have medical infertility problems.

The provision of public funding for fertility treatment in New Zealand contrasts strongly with the Australian government's support for infertility treatment. Australia is the only country in the world with unlimited public reimbursement for assisted reproduction. There, the government pays 85 percent of the cost with the 'patient' contributing 15 percent, as a shared responsibility (Dill, 2002:3). There are considerable calls from consumers in New Zealand to have more public funding of infertility services.

Appendix 18: Legal and ethical aspects

There are a number of laws that have implications for fertility treatment in New Zealand, and many complex ethical issues have emerged as assisted reproduction has proliferated throughout the world. See Gordon and Barrow (2000) for an international perspective on the legal and ethical aspects of infertility counselling.

Te tiriti o Waitangi, the Treaty of Waitangi is an important document for the discussion and development of fertility treatment in New Zealand (Atkin & Reid, 1984; Dyall, 1999) in terms of recognising Maori interests and values. The vital issue for Maori people concerns donated gametes and embryos, as the 'seed that is shared between people to create life' is seen as tapu or sacred, for it establishes relationships between people and whakapapa or genealogy is shared. The concept of whangai or kinship provides a traditional alternative for Maori in the centre of the growing rates of abortion or infertility (Dyall, 1999:36).

The Adoption Act has relevance to assisted reproduction. However, it has not been thoroughly revised since 1955, and upholds 'ignorance, secrecy and concealment' (Else, 1999:59), although the Adult Adoption Information Act was passed in 1985 to give adult adoptees access to information held regarding their birth parents. The main issues involve the open and legal identifying of donors, the transfer of genetic information. While Aotearoa/New Zealand is said to be leading the world in terms of openness around children born from donor insemination or into adoption, this is inadequately reflected in law (Adair & Rogan, 1998; Coney & Else, 1999). Counsellors within fertility clinics address the issue of 'disclosure' to people using donor gametes and encourage openness for the purpose of giving donor children the right of access to information about their genetic origins. The right and responsibility of whether to tell children of their origins rests with parents, some of whom wish to appear as 'normal' as possible and minimise the perceived 'threat to family relationships' (Adair & Rogan, 1998:268). See McRoy and Grotevant (1988) on practice and policy issues of open adoptions.

Children's interests in assisted reproduction are seen as ethically essential (Cooper, 1997; Hildt & Mieth, 1998), but there is a lack of clarity about how to apply this. The Convention of the Rights of the Child which New Zealand adopted in 1989, can be interpreted as giving the child rights in terms of knowing his or her identity and continuing relationships with the birth or genetic family (Coney & Else, 1999:44). Legally, under *the 'Status of Children' Amendment Act* of 1987, the male partner of the woman inseminated with donor sperm is regarded as the legal parent of any resulting child. This currently extends to the child's birth certificate. The donor has no legal rights or responsibilities regarding that child. These men are unpaid, except for travel costs, and either known to the recipients as personal or known donors, or remain anonymous as altruistic or unknown donors. The same applies to egg donors.

The Human Rights Act of 1993 states that it is illegal to discriminate in the provision of services on a wide variety of grounds. Under this act, fertility clinics are now legally bound to provide treatment to paying consumers, notably single and lesbian women (who are not entitled to government subsidised treatment until female infertility is medically established, unlike women in heterosexual relationships). The same Act specified that at least two of the priority ranking criteria outlined above were not lawful - a woman's age and family size. In addition, a woman's Body Mass Index (or BMI) may also be discriminatory. However the government is exempt from this law (Coney & Else, 1999:24) and the priority system was implemented in part to clear the large waiting list of people trying to access public funding for infertility treatment. There is tremendous public debate over the priorities for limited infertility funding and what ethical boundaries should exist for assisted reproductive technologies in this country and internationally.

There are two main guiding bodies that have input into the provision of fertility services in New Zealand. *The Reproductive Technology Accreditation Committee (RTAC)* has provided accreditation for all infertility services in Australia and New Zealand since 1990. *The National*

Ethics Committee on Assisted Human Reproduction (NECAHR) was set up in 1995 to review new or untried ART proposals of importance to New Zealand; to develop protocols and guidelines; and to provide the Minister of Health and the National Advisory Committee on Health and Disability Ethics with advice on issues regarding assisted reproductive technologies.

FertilityNZ, formally known as The New Zealand Infertility Society, was established in 1990 to provide support and information for those experiencing infertility; raise the public awareness of infertility issues; network between regional organisations; to represent consumers on RTAC; and advocate for better funding for infertility services. Local support groups have been set up around the country to assist people faced with infertility and moving on from treatment (See Clifford et al, 2001; Daniels, 2001; Labett, 2001, Shapiro, 2000). This organisation plays an important role at personal, professional and political levels to bring people together and improve infertility services, in the face of limited government support.

In 1998, *the Human Assisted Reproductive Technology Bill* was proposed and is currently being considered along with Diane Yates' Private Members Bill. It prohibits certain unethical techniques, like cloning, slightly increases the role of NECAHR (the ethics committee on assisted reproduction, noted above), and importantly provides rights of access to information for egg and sperm donors and children born through donated gametes. In New Zealand, it is recognised that donor children have a right of access to information about their genetic origins. Only donors who are prepared to be potentially identifiable to resulting children are selected by fertility clinics, keeping detailed records, although donors are likely to remain anonymous to recipients. Under this Bill, the Registrar-General of Births, Deaths and Marriages holds a centralised system of information holding about donors of gametes, embryos and donor children born.

Appendix 19: Infertility and childfree

Couples without children are often assumed to be 'childfree'. While indeed 'free' of children, this term has the connotation of wanting and choosing to be free of children. Childfree is a less suitable term for people actively struggling with infertility, because they are not exercising a choice in the matter (Diamond et al, 1999:3). The truth for those experiencing infertility is that childlessness is an involuntary situation - if choice could be exercised children would be born and present in the family. This is an important distinction, both for those who consciously choose to be childless for a variety of reasons and those who have the pain and frustration of not being able to control their fertility to have the children they desire.

In studying New Zealanders who choose not to have children, Cameron (1990, 1997) also found a challenging population to study (similar to the infertile population not having treatment). Not only are they difficult to find, defining voluntary childlessness is problematic, and there are the issues of time frame to realistically gauge childlessness and the true motivation for the childless state. For those people who are childless and either single or in a same sex relationship, the assumption and acceptability of childfree status is generally made by society. This may not be the case, as single women may be waiting to find a suitable partner to have children with, or like lesbian women, may be seeking a suitable sperm donor. Therefore, any decision to pursue having children clearly needs to be made involving another person and often a fertility clinic.

Voluntary and involuntary childlessness exist on a continuum (Letherby, 1999; Monarch, 1993), where a number of people are delaying a decision or are undecided about whether they really want children, being open to children coming along or not. This state of openness or 'non-decision' (Cameron, 1997) has some commonalities with the state of treatment decision limbo, recognised and explored in this study. At some point, most people in a heterosexual relationship will at least talk about and take measures to either use contraception to avoid pregnancy or cease using contraception to be open to pregnancy. As women approach the age of forty, positioning on this continuum becomes more conscious, as the implications for a future with or without children is brought into sharper focus. As fertility declines with age, this impacts on the prevalence of infertility and has direct implications for infertility treatment decisions.

There are some authors writing on infertility (Carter & Carter, 1989; Deveraux & Hammerman, 1998; Ferguson & Peoples, 1998; Johnston, 1994) who argue that those people who consciously choose to stop infertility treatment are moving from being 'childless' to 'childfree'. Even though these people may have spent years actively trying to have children, at some point they decide that they want to make a positive, life-affirming choice to have a good life without children. This decision allows for peace; relief; the acceptance of one's life as it is; the opportunity for new growth and new goals; and the investment of renewed energies into work, relationships and interests (Sewall, 2000).

For some, this involves using contraception or sterilisation, telling others of their decision not to try any more and making quite different choices with travel, personal interests and items such as car and house size. Some infertile people who have consciously moved on to become 'childfree' are reluctant to discuss their choice, because: other infertile people may feel threatened, parents may be disappointed and friends often do not understand (Carter & Carter, 1989). This results in feelings of isolation and a lack of support. Along with the voluntarily childless discussed above, being 'childfree' does not mean that children are disliked, that meaningful long-term relationships with other's children are not present or that feelings of loss are permanently erased.

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