

**Misguided hope: a narrative analysis of
couples' stories of childlessness despite
treatment with assisted reproductive
technology**

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By

Kathleen Peters

Bachelor of Nursing (Honours) (University of Western Sydney).

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Abstract

Societal expectations for procreation often result in infertile couples accessing assisted reproductive technology (ART). In the current state of this technology, the successful outcome of the birth of a child does not always occur. This study contributes to nurses' understanding of what it is like for couples to remain involuntarily and permanently childless after infertility treatment has ended, and aims to bring about change in attitudes and practice towards this group. Literature that acknowledges individuality as well as shared experience for couples who remain childless after infertility treatment is scarce. Health professionals may therefore encounter difficulties in providing this group with appropriate support.

This research used a qualitative approach informed by feminist perspectives to gather stories of five couples' experiences of childlessness after accessing ART. Individual conversations with both members of the marital partnership were recorded, transcribed and analysed.

The study found that due to the societal expectation of procreation, and the falsely elevated 'success rates' of ART, couples often delayed decisions about whether they should persevere with treatment, hence reducing the possibility of exploring alternative methods of parenting. As well as highlighting the ambiguity of the term 'success', the study suggests that the hope that technology brings childless couples prolongs decision making and simultaneously serves to compound the sense of failure experienced by these couples. The couples' engagement with ART, as well as their inability to conform to the normative family of parents and their biological children, also contributed to periods of isolation. Following the

decision to remain childless, the participants found that setting achievable and challenging goals assisted in re-building their self-esteem, and enhanced the process of adapting to their life without children. Although participant couples expressed obvious grief at remaining childless, they also showed resilience by managing attached difficulties and stigmatisation, and by creating positive future outcomes. For these childless couples, the strength of their relationships was seen as critical in the process of overcoming adversity. This study suggests ART clinics should provide more realistic information to individual couples regarding the likelihood of taking home a baby. Further to this, independent counselling support is recommended for couples prior to and during ART treatment, and when this treatment is ceased.

Declaration

I certify that this thesis does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Kathleen Peters

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Glossary and abbreviations

Artificial insemination (AI): injection of semen into the vagina, uterus, or fallopian tube to assist fertility.

Assisted reproductive technology (ART): all treatments and procedures that include the *in vitro* handling of human oocytes, sperm and/or embryo with the intention of establishing a pregnancy.

Azoospermia: Absence of spermatozoa in the semen.

Biochemical pregnancy: pregnancy evidenced by raised levels of urine or serum human chorionic gonadotrophin (hCG).

Bromocriptine: (trade name Parlodel) a dopaminergic drug prescribed for men with hyperprolactinaemia. Found to be successful in reducing prolactin levels in these men, thereby enhancing sperm production.

Clinical pregnancy: Any type of pregnancy, apart from those diagnosed only by elevated β hCG levels, including ectopic pregnancy, blighted ovum and spontaneous abortion

Clomiphene Citrate: (trade names Clomid, Serophene) a drug that indirectly stimulates secretion of FSH and LH by blocking receptors for oestrogen and testosterone in the hypothalamus. Prescribed for both male and female infertility. In men it aims to enhance sperm quality and production. In women it is used to correct irregular ovulation, stimulate ovulation and increase oocyte production.

Controlled ovarian hyperstimulation (COH): Treatment with medications that induces the development of multiple ovarian follicles to obtain multiple oocytes for aspiration. Also referred to as a stimulated cycle or ‘stim’ cycle.

Dilatation and curettage (D&C): Surgery where cervix is dilated to allow curettage of the endometrial lining. Commonly performed after miscarriage to eliminate retained products and prevent infection.

Embryo transfer (ET): Procedure whereby one or more embryos is placed into the uterus or fallopian tube.

Endometriosis: The presence of endometrial tissue outside the endometrial cavity.

Euspermic: normal sperm count.

Gamete intra fallopian transfer (GIFT): A procedure that transfers both oocytes and sperm to the fallopian tubes.

Human chorionic gonadotropin (HCG): The hormone that maintains the corpus luteum for the first three months of pregnancy.

Intracytoplasmic sperm injection (ICSI): IVF procedure in which a single sperm is injected into an oocyte.

In-vitro fertilisation (IVF) – Fertilisation of an oocyte by a sperm in-vitro.

Live birth: A birth in which a foetus is delivered with signs of life after 20 weeks gestation.

Oligoasthenospermic: Low sperm count.

Oocyte: Ovum, an unfertilised egg.

Ovarian hyperstimulation syndrome (OHSS): A potentially fatal complication of ovarian hyperstimulation in which there is an enlargement of the ovaries, a large fluid shift from the vascular space into the peritoneum, increase in blood viscosity resulting in thrombosis, possible renal compromise and pulmonary oedema. Forms of this syndrome may be mild to severe.

Polycystic ovary syndrome (PCOS): A chronic syndrome or disorder characterised by the presence of multiple benign cysts on the ovaries.

Preimplantation genetic diagnosis (PGD): Examination and screening of cells from embryos prior to embryo transfer in order to detect genetic/chromosomal disorders.

Tamoxifen: a selective oestrogen receptor modulator, administered selectively to males with idiopathic oligospermia to increase levels of testosterone, luteinizing hormone and follicle stimulating hormone and therefore enhance sperm numbers and function

Viable pregnancy: A pregnancy of at least 20 weeks gestation.

Zygote: The cell that results from the fertilisation of an oocyte by a sperm.

Zygote intrafallopian transfer (ZIFT): A procedure in which a zygote is placed into the fallopian tube.

Transcription glossary

Participants have been provided with pseudonyms to ensure confidentiality

Participants' stories directly quoted from interview transcriptions are presented in italics and take the form of the example below:

Rosemary (p. 2-3): I had my pregnancy confirmed on 19 December, I remember that.

[] square brackets indicate words or phrases that have been substituted for the names of people, places and other identifying material.

() parentheses indicate words or phrases inserted into the transcripts for clarification and/or to indicate emotions such as laughter or tears

Bold italics underline words emphasised by participants

... three dots indicates a pause of approximately two to three seconds

Chapter One

SETTING THE SCENE

*I never really knew what it was like to go to bed at night and not weep
Weep for the child we longed for
Weep for the reasons it wasn't beginning
Give me a reason – give me a cure
But no. Not to be.
I had no option but to get over it.
But it is there, just under the skin.
Weeping and wailing
But thankfully controllable, manageable.
But always there
(Pamela Newman, 2001)*

In most cultures there is a strong expectation that married couples will create a family through the birth of biological children. Indeed, the desire to procreate is frequently cited as one of the main reasons people choose to marry, and many people do so in the belief that they will have children. This desire to reproduce is attributed to both a biological urge – an inherent instinct – as well as a societal and cultural expectation. However, not all individuals are able to or choose to reproduce. The reasons people do not reproduce are varied and include personal choice, inability to find a suitable partner and infertility to name but a few. Those who do not conform to societal expectation and produce a biological child are often excluded from a variety of social activities. This thesis explores the experiences of married couples who have not produced a biological child and

elected not to pursue parenthood by other means as one or both of the partners have been diagnosed as infertile.

This chapter provides insights into the expectations of married couples to reproduce and how this may lead infertile couples to access assisted reproductive technologies (ART). Also addressed are the implications for couples when this technology fails, and current roles of the ART nurse. A thesis overview is provided as a guide for each chapter. Finally, this chapter states the aims of the current research and briefly indicates its use of a qualitative methodology informed by feminist perspectives.

Infertility affects as many as one in six Australian couples at some stage of their reproductive lives (Fertility Society of Australia [FSA], 2004). Of couples who access assisted reproductive technology (ART), approximately 40% of cases are due to male infertility (McLachlan & de Kretser, 2001), 40% female infertility and the remaining 20% are considered to be of mixed or unknown causes (Monash IVF, 2001a). Currently, infertility is simply defined as the failure to achieve a pregnancy after twelve months of unprotected intercourse or the inability to continue pregnancy to a live birth (FSA, 2004; Gibson & Myers, 2000; Johnson, 1996; Milne, 1988;). This murky definition is problematic, as fitting these criteria does not necessarily mean that a couple is medically infertile. Becoming pregnant is dependent on many factors with perhaps the most obvious being the regularity of intercourse within the fertile period of a woman's menstrual cycle (te Velde & Cohlen, 1999).

Infertility and its treatments

Women and ART

Infertile couples may access ART in the hope that it will result in a biological child. ART includes such procedures as in vitro fertilisation (IVF), gamete intra fallopian transfer (GIFT), donor gamete cycles, intracytoplasmic sperm injection (ICSI), and artificial insemination (AI) (Monash IVF, 2001b; Rowell & Braude, 2003). IVF was first initiated in order to assist women with fallopian tube defects to achieve a pregnancy. It involves a process that begins at the commencement of a woman's menstrual cycle. The woman must undergo a series of blood tests to check hormone levels and she receives daily injections that aim to stem ovulation and encourage follicle growth. After approximately two weeks of hormone treatment, an ultra sound is performed to assess the number of follicles present on the ovary. If enough follicles are present to warrant an egg pick-up, the procedure is carried out either trans-vaginally or laparoscopically. Sperm is then supplied via masturbation and placed with the ova in a petri dish to fertilise. The couple must then wait 18-24 hours to find out how many eggs are fertilised. Embryo Transfer (ET) is the next step of the process occurring between 24 to 72 hours after egg collection. This involves the doctor passing a catheter containing the embryos through the woman's cervix and into the uterus, where hopefully one or more of the embryos will attach. If the woman has not commenced a menstrual period within two weeks after ET, a blood test is performed to ascertain whether a pregnancy has been achieved. Due to the hormone therapy necessary for the cycle, the woman may have signs and symptoms of pregnancy such as nausea, vomiting, tender and enlarged breasts without actually being pregnant. This adds

to the emotional distress experienced after an unsuccessful IVF cycle (Barber, 1994; Monash IVF, 2001b; Prosser, 1997).

Gamete Intra-Fallopian Transfer (GIFT) is a similar process to IVF except that it is offered to those women who have healthy fallopian tubes (Monash IVF, 2001b; Rowell & Braude, 2003). The preparation of the ovaries and uterus remain the same, but after egg pick-up the eggs are mixed with the sperm and placed directly into the fallopian tubes using a laparoscope (Monash IVF, 2001b; Rowell & Braude, 2003). Ideally with this process, the egg and sperm fertilise in the fallopian tube as would occur naturally. Unlike IVF, however, the woman requires a general anaesthetic for this procedure (Monash IVF, 2001b; Prosser, 1997; Rowell & Braude, 2003)

Donor gamete cycles involve gametes being donated to couples who are unable to provide their own healthy ova or sperm for fertilisation, with the purpose of providing an embryo for transfer (Monash IVF, 2001b). ICSI is a procedure used for the more severe forms of male factor infertility. It involves the injection of a single sperm directly into the cytoplasm of the egg, thus increasing the chances of egg fertilisation in these couples (Monash IVF, 2001b; Rowell & Braude, 2003).

Men and ART

There is a paucity of literature available on men's experiences of infertility and childlessness even in light of clinical evidence pointing toward an increase in male reproductive problems (Boisen, Main, Rajpert-de-Meyts, & Skakkebaek, 2001). A fact that is not widely publicised is that some men are actually subjected to infertility treatment in the form of infertility drugs. Testosterone replacement therapy may be initiated in men with hormone abnormalities to enhance the

production and quality of sperm (Williams, 2002). The adverse effects of this therapy may include irritation at administration site, acne, weight gain, gynecomastia, oedema, fluctuations in libido and mood, with prolonged use being associated with hepatic carcinomas (Winters, 1999).

In rare cases, clomiphene citrate¹ may be administered to men who are oligospermic (i.e., those who have low sperm counts) in order to enhance sperm production (Gonzales, Salirrosas, Torres, Sanchez, & Villena, 1998; Kadioglu, Koksal, Tunc, Nane, & Tellaloglu, 1999). Further drugs such as tamoxifen², gonadotrophins, antibiotics, and corticosteroids, which have adverse effects such as peptic ulcer disease, glucose intolerance, skin disorders and fluid and electrolyte disturbances, may all be prescribed for the infertile male (Haidl, 2002; Lehne, Moore, Crosby, & Hamilton, 2001). Bromocriptine³ is also prescribed for men with impaired sperm production and often causes dizziness, headaches, nausea and vomiting, and may cause orthostatic hypotension (Lehne et al., 2001; Liu & Handelsman, 2003)

The inequalities in infertility treatment associated with women being recipients of more invasive procedures are acknowledged in the literature (e.g., Rowland, 1992; Steinberg, 1990). This same literature also excludes the possibility that men are increasingly subjected to invasive procedures. Such procedures include transrectal ultrasounds, indicated in azoospermic⁴ patients to determine whether

¹ Clomiphene citrate (trade names Clomid, Serophene) – a drug used to block receptors for oestrogen which aims to enhance sperm production (Liu & Handelsman, 2003).

² Tamoxifen – a selective oestrogen receptor modulator, administered selectively to males with idiopathic oligozoospermia to increase sperm numbers and enhance sperm function (Kadioglu et al., 1999; Lehne et al., 2001)

³ Bromocriptine (trade name Parlodel) – a dopaminergic drug given to decrease prolactin levels with the aim of enhancing sperm production (Liu & Handelsman, 2003).

⁴ Absence of sperm in semen

obstruction of the ejaculatory duct is present; scrotal ultrasounds, performed when clinical findings are inconclusive or a testicular mass is suspected; testicular biopsies, needle aspiration or open biopsies for sperm collection. Surgical exploration, vasography and seminal vesicle vesiculography are an increasingly common occurrence in the infertile male (Jarow et al., 2002; Khorram, Patrizio, Wang, & Swerdloff, 2001). Consequently information regarding the impact of ART on both men and women is required to ensure appropriate delivery of care by nurses and other health professionals.

Nursing and ART

The role of the nurse in the area of ART is expanding and evolving continually to accommodate the constant developments in reproductive technology (Fertility Society of Australia [FSA] Reproductive Technology Accreditation Committee [RTAC], 2002; Morris, 2001). Nurses' job descriptions and responsibilities vary across various demographic areas and clinics and may include initial consultations, trans-vaginal ultrasound scanning, intrauterine inseminations, embryo transfers, determining the need for and administration of medication, sperm preparation and pregnancy tests (FSA RTAC, 2002; Morris, 2001).

Within both the basic and extended roles of the nurse working in the area of reproductive medicine, FSA RTAC (2002) asserts the importance of providing nursing care, counselling and advocacy to their patients. Further to this, the nurse working in ART is responsible for providing information and education to their patients, maintaining accurate documentation of patient records, conducting and participating in nursing research, participating in quality assurance, understanding legislation and regulations pertaining to ART and professional development (FSA RTAC, 2002). As nurses are increasingly extending their role, involvement of

fewer health professionals is necessary (Morris, 2001). The nurse's role in ART is therefore pivotal to the understanding gained by infertile couples who access and engage in this technology. A comprehensive understanding by couples of ART and related consequences is imperative for informed consent and may serve to prevent couples subjecting themselves to various procedures and treatments simply because it is what is expected.

Couples and ART

Regardless of whether the reason for infertility is male or female related, women undergo most if not all of the invasive and often embarrassing procedures of ART (Carmeli & Birenbaum-Carmeli, 1994), and may participate in these procedures without questioning or perhaps without comprehending both physical and psychological consequences of treatment (Peters, 2001). A participant in a study by May (1995, p. 211) stated that she felt guilty for not doing everything in her power to achieve a pregnancy, even though she had a nice life without children. Comments such as this highlight how the social pressure impacts on women, fuelling their drive to reproduce and become mothers.

The negative effects that ART has on all aspects of life including the couple's relationship are evident in Remennick's (2000) work where a participant states 'Wouldn't it be wiser from the outset to make peace with our state (of childlessness) and to invest energy into other life projects?' (p.837). In theory, this may be the rational thing to do, although it is very difficult due to the stigmatisation of remaining childless and the beliefs of childless couples that procreation is a marital obligation and parenthood a natural and very essential part of life. With the traditional ideal of family persisting in today's society despite structural changes in society (Andersen, 1991), to gain social approval women

may attempt to conceive without giving the notion of motherhood much thought or planning. When couples encounter difficulties, they resort to technologies on offer to achieve this societal expectation. Rose (2005) refers to these technologies as ‘technologies of hope’, to show some of the mechanisms that engage people in the technology irrespective of the technology’s actual capabilities. This offered hope, May (1995) states, makes infertility more affectively wrenching: because ART offers hope of a cure, it makes it difficult to cease treatment, resolve one’s feelings and accept childlessness.

Additionally, ART is both physically and psychologically stressful, making stringent demands on a couple’s time and with the stigma attached to infertility having detrimental psychological and social repercussions. In addition, ART comes at a significant financial cost, thus intensifying the apprehension experienced by a couple in the already stressful quest for a biological child (Kuczynski, 1989; Schoener & Krysa, 1996)

Although ART is often regarded unfavourably, with procedures classed as expensive and unnatural, there is continued emphasis on the importance of biological parenthood, thus creating a no-win situation for infertile couples. This attitude could result in couples pursuing pregnancy via ART regardless of their chances of success, rather than considering other avenues of parenting (Miall, 1994; te Velde & Cohlen, 1999). Furthermore, as Rose (2005) reveals, some ART clinics exaggerate success rates for marketing purposes, thus providing infertile couples with further hope that this technology will provide them with a biological child.

ART ‘success’ rates

Quoted success rates are often ambiguous and may vary greatly between clinics, with some boasting success rates up to 78% (Hull et al., 1992). Factors such as the age of treated women, the number of embryos transferred, the number of cycles undergone, various techniques and the reason for infertility are often manipulated to enhance final published results. However, most clinics agree that the first IVF cycle holds the greater chance for success than does any subsequent cycle, and the increase in maternal age inversely relates to success rates for assisted reproductive procedures (Hull et al., 1992; Jansen, 2003; Monash IVF, 2001b). McCall (1996) highlighted that whilst ART provides a ‘miracle cure’ for some infertile couples, IVF ended in failure for three out of four childless couples.

However, the blame for non-conception is placed squarely at the feet of the infertile couple and not at the more deserving failed technology, with some literature suggesting that increased anxiety levels negatively affect the outcome of IVF-ET (Facchinetto, Volpe, Matteo, Genazzani, & Artini, 1997). This technology does not always provide a successful outcome. When the decision is made to cease ART treatment without achieving a pregnancy, and in the absence of a biological child, a multitude of issues arises, not the least of which is a confrontation with those societal norms and the concept of family.

Procreation for familial status

A ‘normal’ family is generally considered as the nuclear family unit of a heterosexual couple and their biological children (Andersen, 1991, p. 235). The state of childlessness could therefore be seen as excluding a childless couple from the title of family. The term *childless* implies that it is traditionally accepted for

couples to have children, and that not to have children is to be considered different from those who have children (May, 1995). Both Wegar (2000) and Zucker (1999) concur with this view and assert that childless couples are devalued, irrespective of whether they hold any control over their reproductive status.

Involuntary childlessness is a state where couples experience a loss of control over their reproductive choice, resulting in many reactions one of which is a grief response. Individuals and couples who have lost the ability to govern their reproductive futures endure extensive emotional turmoil associated with both loss and a sense of failure of what they are unable to achieve (Daniluk, 1996; Peters, 2001). Those who have children fuel the severity of these reactions by devaluing those who remain childless, and insisting that they prove their worth in other aspects of their life to compensate for this failure in reproduction (May, 1995).

Although infertile couples may embark on a journey to procure a child either through ART, adoption or surrogacy, they may still be considered as inferior to couples who have not experienced reproductive difficulties. Letherby (1999) highlights the hierarchy of motherhood that maintains that women who have children conceived naturally are superior to those who have adopted children or children born with the assistance of ART. So important is procreation to society that women and men are encouraged to marry and reproduce, being rewarded with lavish marital ceremonies with reference to procreation present in some marital vows. Those who reproduce are rewarded by governments for their efforts in the form of some financial support and tax exemptions that in some countries increase proportionally with the addition of further children to the family (Cain, 2001, p.xi; Rowland, 1992). To maintain maximum productivity, governments

encourage women to remain an active part of the workforce, while at the same time reinforcing the importance of reproduction, by ensuring childcare, education and welfare support for families.

The many theories surrounding infertility and childlessness accentuate the placement of societal blame primarily at the feet of the infertile couple, with the majority of this blame being directed at the woman of the union under scrutiny. Of the many theories surrounding infertility and childlessness, psychological explanations are most often from this familial perspective. Blame is directed at couples for not being psychologically ready to have children, with infertility branded as one of nature's fail-safe mechanisms in those who are not psychologically healthy enough to nurture (May, 1995; Rowland, 1992).

Infertility and childlessness reportedly holds different meaning for men and women. Edelmann and Connolly (1996) suggest that the issue for infertile males is primarily associated with a loss of manliness rather than a loss of parenthood, whereas women's primary concern is the loss of motherhood. Wirtberg (1999) also proposes that men are less concerned about parenthood and more concerned with their role as a husband. Further to these claims, Glover, Abel, and Gannon (1998) identify that men perceive their infertility and treatment failure as more of a threat than a loss, so counselling that is appropriate for women (which is claimed to be similar to bereavement counselling) is not necessarily appropriate or therapeutic for men.

May (1995) found that women were more likely than men to express the pain and isolation of childlessness. Due to the sensitive nature and social implications of male infertility, men may be less likely to draw attention to the issues they

associate with this phenomenon. It is obvious that there are differing opinions regarding the effects that infertility and childlessness may have on men and women. Men's experiences may well encompass issues that differ from the way in which women perceive their experiences of this phenomenon. The intention of this research is to acknowledge both differences and similarities in the context of the 'couple' relationship and the meaning of infertility and childlessness as experienced by both partners collectively. To ensure individual stories are gathered, and that equal opportunity is given to each partner to voice their accounts, conversations with partners of the couple were held separately. This allowed the research questions to explore both 'What is it like for couples to unsuccessfully undertake ART and remain childless?' and 'Do men and women have different stories to tell?'

For the purpose of this research, the term couple refers to married heterosexual couples. This decision was taken because same-sex couples, single individuals and those in de facto relationships may not have the same societal pressure on them to procreate and are very often excluded from accessing options such as ART. For example, a participant in the study by Peters (2001) explains that after being divorced and now living in a de facto relationship, 'There's no expectation of me to have children if I'm not married.' (p.84). While it is acknowledged that same sex couples, single individuals, those in de facto relationships, and infertile couples who choose not to access ART may have significant issues concerning infertility and childlessness, they remain outside the scope of this study.

Situating myself in the research

I come to this research as an infertile childless woman, a wife, and a nurse. My own experiences of infertility treatment, my observations of nurses' interactions with others accessing ART, and my own prior research in this area, indicate the necessity for significant changes and improvement in care delivered by my colleagues in the area of assisted reproduction.

For most of my young adult life I endeavoured to conceive and bear a child without focusing on the future. I have been questioned numerous times regarding my reproductive capacities and intentions, with innuendoes of narcissistic tendencies as a rationalisation for my childlessness, and further probing for the purpose of laying blame for my reproductive failure. I have been given a multitude of advice from well-meaning friends and acquaintances pertaining to my apparent heightened stress levels, my diet, my career and even sexual positions that would inarguably assist in achieving a pregnancy. This constant stream of advice has led me to believe that perhaps it is more difficult for others in society to come to terms with my childlessness than it is for me.

I recognise that throughout my own experiences pursuing infertility treatment and the on-going healing process associated with remaining childless, my husband suffered as well. He may not have been through the rigorous physical treatments and procedures but he was subjected to being an observer of my pain. As a result, I come to this research not purely as an advocate for the infertile childless women of society, but also for the men, whose ability to deal with issues surrounding infertility and childlessness can impact greatly on their partners. Although credit is not duly given to males who are part of the infertile couple and who also remain

childless, the issues surrounding childlessness may hold social consequences as grave for men as for their female counterparts. I believe men should be encouraged to voice their emotions relating to infertility and childlessness as this directly impacts on the couple's relationship. If both partners are able and encouraged to express themselves regarding the phenomena in question, then issues may be more easily resolved, assisting in the health of the couple's relationship.

I believe that health professionals and nurses in particular should act as advocates for their patients, offering all options available to them and then supporting their decisions, regardless of their own beliefs and biases. I believe that infertile couples have the right to remain childless without fear of being ostracized by those in society who perceive this as a deviance from the norm. I believe that people should be valued irrespective of their reproductive capabilities, and that procreation is merely one way of contributing to the reproduction of society.

I believe that understanding comes with education and life experience and because it is impossible for nurses to experience every phenomenon affecting those they care for, education gained through research provides an essential tool in order for nurses to deliver appropriate care. Above all, I believe that nursing is a caring profession, and that highlighting the magnitude of the effect that infertility and subsequent childlessness has on couples will encourage nurses to review their current practices to ensure a more sensitive and fitting response in caring for these couples.

Aims of the study

This study aims to contribute to nurses' understanding of the experience of remaining involuntarily and permanently childless after infertility treatment has ended. This research also aims to provide nurses with increased awareness and knowledge regarding the individual reactions and needs of both men and women when faced with remaining permanently childless after the rigours of ART. By increasing awareness and generating an understanding of this phenomenon through participants' narratives, nursing practice will be informed, thus leading to the delivery of appropriate and sensitive care. Finally, this research aims to raise the profile of this marginalised population within not only healthcare settings but society in general.

The significance of this study is that it has the potential to generate new knowledge for nurses and other healthcare professionals working in the field of ART regarding experiences encountered by these couples. This new knowledge will improve current practice, thus minimising the negative effects of treatment failure to childless couples. Through expanded knowledge, nurses will be equipped to provide realistic care, conveying the possibility of treatment failure and introducing various options for a fulfilling life other than biological parenting.

Using feminist narrative methodology

Infertility, involuntary childlessness and treatments couples may access in the hope that they will have a biological child may superficially seem a private issue. However, this seemingly private issue is fraught with public and political implications. Therefore this research utilises a qualitative methodology informed

by feminist perspectives in order to look at structural, personal and political issues related to couples' initial and continued engagements with assisted reproductive technologies and the sequelae associated with treatment failure.

Sandelowski (1994) conveys that in an attempt to bridge the gap in infertility practice between scientific generalisations and their application to the individual case, nurses should pay closer attention to an individual's narrative (p.752). Through a narrative analysis of participant couples' stories, the current study seeks to enlighten nurses and other health professionals regarding couples' experiences of infertility, ART failure and subsequent childlessness in an attempt to bridge this gap.

Listening to participants' individual stories as well as those shared within the dynamics of the couple is considered essential, as couples are seldom asked to talk in such depth about the aftermath of ART treatments. Furthermore, storytelling enhances nurses' and other health professionals' understanding of situations, and of individuals within those situations (Banks-Wallace, 1999; Benner, Tanner, & Chesla, 1997; Bowles, 1995; Cronin, 2001; Pennebaker & Seagal, 1999). Remaining childless despite treatment for infertility is a topic that has not been adequately explored and is therefore poorly understood. Understanding the experiences of participant couples through their stories will provide valuable knowledge regarding these couples' needs, leading – it is hoped – to appropriate support and advocacy from nurses and other health professionals.

Thesis Overview

The first three chapters of this thesis provide an introduction to the topic, a literature review, and insights into the methodology and methods that underpin

this work. The following three chapters make up the substantive content of this thesis. They are structured to present the stories of participant couples, including a discussion on the dominant underlying stories and provide a summation or conclusion to each respective substantive chapter. The final chapter is the overall conclusion for the thesis and provides an overall summation, bringing together the major findings of the thesis.

This chapter, **Chapter One**, has provided background information on the importance a biological child holds to couples in the context of personal and societal expectation and the technology they may access in an attempt to fulfill this expectation. Also presented in this chapter is a personal account that situates me within the research, acknowledging subjectivities that influence the direction of the thesis. Finally, the aims and significance of the research are stated as well as a brief justification of the chosen methodology.

Through a detailed review of the literature **Chapter Two** provides insights into the importance a biological child holds for couples and why they may access ART. Implications of infertility, its treatments and treatment failure are explored in order to provide background knowledge for the reader as well as to identify and illuminate gaps in the available research, thus justifying the current study.

Chapter Three defines the elements that informed this research and provides a comprehensive account of how this research was executed. Feminist perspectives were integral to the current study's use of a qualitative research methodology, in order to foster opportunities for social change in attitudes and practice whilst taking into consideration the impact of research procedures on the participants of the study.

Chapter Four is the first of three chapters that present participant couples' stories. This chapter describes the pathways through treatment for couples' from their diagnoses as infertile to when they made the decision to cease ART treatment. Common stories among participants illuminate issues surrounding the hope and expectations, as well as the difficulties, associated with this 'hope technology'.

Chapter Five presents an account of the realisation by participant couples that they will remain involuntarily childless and their reasons for their decision not to further pursue parenthood by alternative methods such as adoption or surrogacy. Dominant stories throughout this chapter encapsulate feelings of guilt and failure in response to couples' inability to fulfill societal expectation by becoming parents.

Chapter Six presents stories that convey the ways in which participant couples cope with remaining childless and the ongoing issues they face throughout their life course. Stories throughout this chapter tell of grief experiences and couples' abilities to remain resilient despite continual adversity.

Chapter Seven concludes the thesis and includes a summation of findings, outlines the limitations of the research, makes suggestions for change in practice, sketches directions for further research and offers a review of recent like literature for the purpose of comparing findings.

Conclusion

This introductory chapter provides some insights into the social pressures placed on marital couples to produce biological offspring and the ways in which they may strive to fulfill this societal obligation. For those who access ART in the

hope of a ‘cure’ for their infertility, ‘success’ is often evasive. The impact on couples, both as individuals and within the dynamics of a couple for whom treatment fails is an area that has thus far been inadequately researched. The following chapter provides further detail regarding available literature surrounding the various implications of infertility and remaining involuntarily childless despite access to ART.

Chapter Two

INFERTILITY, ITS TREATMENT AND SEQUELS

*I presented my aging mother with a framed photo of herself as a 20 year old.
So beautiful, so carefree.
She cried – no-one had ever given her a framed photo of herself before.
Then it flooded back.
Could my children have looked as beautiful as her?
Would they have her fine features, dark skin?
These things robbed of me forever.
No turning back now, no hopes, too old for dreams.
Incredible what happened to me, tragic –
Worse than the world's greatest disasters
(Pamela Newman, 2001).*

Introduction

From birth, we are socialised to reproduce, with societal expectations mounting when couples marry. The inability to procreate has the capacity to impact greatly on couples, both emotionally and socially, and in contemporary Western society, couples may actively seek intervention to assist in the pursuit of biological parenthood. For those who choose to pursue ART in the hope that it will provide them with a biological child, there are additional emotional and social pressures. Furthermore, these often couples face financial and physical ramifications

The previous chapter provides insights into the importance a biological child holds for couples and why they may access ART. This chapter builds on this overview, providing a more detailed review of literature related to the implications of infertility, its treatments and treatment failure. This review provides background knowledge for the reader as well as identifying and

illuminating gaps in the available literature, thus justifying the current study. Psychosocial origins of motherhood and fatherhood are discussed, with further focal issues of this chapter including a review of the literature pertaining to masculinity, stigmatisation, infertility, and ART treatment failure.

Procreation and the social family

Children denoting family

Societal expectation of marital couples is that they will procreate. As Wirtberg (1999) affirms, “it appears that at least for younger couples, a baby is a requirement for the couple to become a family” (p.122). Hepburn (1992) elaborates on this definition by highlighting the opinions of those in authority that family is a natural group unit of society, and that marriage is spouses committing to use their reproductive capacities to establish a family. Hepburn proposes that this concept of family is embedded in government control over individuals’ reproductive lives (p.3-4). Although the definition of family has now broadened to include unmarried or single parents and blended families (Smith, 2004), and “all the persons living together in one household” (Butterfield, 2003, p. 589), the most common definition remains “a primary social group consisting of parents and their offspring” (Butterfield, 2003, p. 589). The fundamental presence of children within this definition is evident in the literature (such as that by Bryson, Strazzari, & Brown, 1999) where the term ‘family’ continues to be interchangeable with the word ‘children’. It is within this family group that, traditionally, women and men are socialised into specific roles that include their reproductive capacities and obligations.

Motherhood and non-motherhood

Motherhood encapsulates a multitude of themes including symbolic, psychological and interpersonal considerations. These considerations vary between women depending on individual experiences pertaining to psychological, social and economic backgrounds, and the extent of their previous reproductive experiences (Arendell, 2000; LeBlanc, 1999; Wolf, 2001). However, women traditionally share a strong and unique link in their responsibility of reproductive roles, with motherhood providing a pivotal and defining characteristic of womanhood for many women (LeBlanc, 1999). Some feminist literature portrays motherhood as something that has long been forced upon the women of society for the purpose of repression and control by the male population (Meyers, 2001). Whatever the origins of this phenomenon, the role of motherhood is deeply ingrained into a woman's beliefs about a lifetime goal and essential role. Motherhood, therefore, is taken for granted by most women as a natural life transition, and with this role is assumed to come an almost automatic life-time belonging to a unique subset of society.

Gender development literature (such as that by Furnham & Mak, 1999; Jacobs, Bleeker, & Constantino, 2003; Leaper, 2000; Levy, 1999) attests that gender socialisation commences from the birth of a child and is contributed to by various influences in the child's life including parents, teachers, friends and the media. However, the preparation for this socialisation occurs much sooner, with expectant parents and their family and friends choosing colours for nurseries, clothes and playthings and ensuring these items are gender appropriate. Martin, Ruble, and Szkrybalo (2002) confirm the powerful influence of early gender socialisation by highlighting that both gender identification and knowledge have

been found to be present in infants. Egan and Perry (2001) illustrate the significance of gender socialisation on an individual's identity, noting that gender influences many aspects of our lives including employment, relationships and recreational activities.

Peterson and Roberts (2003) elaborate on the parental influence in gender socialisation, arguing that children are more likely to imitate parents of the same sex and therefore same-sex parents become the most influential role model for that child. Prior to recognition of what this role actually involves, the girl child mimics her most influential female role model who is, usually, her mother (Becker, 1990). Infant girls are given dolls and encouraged to 'mother' them (Bergart, 2000). More modern day varieties take the role further, giving children the responsibility of not merely playing at 'nurturing' but also encouraging them to take part in the physical care such as changing nappies and feeding these substitute babies. This typical role-playing scenario can be seen to enforce a mindset of what the 'normal' woman wants and strives for in order to fulfill lifetime goals.

Motherhood, then, for most women comes to be viewed as an integral part of their existence. Indeed it may be seen as being central to a woman's existence, perhaps even without conscious thought or deliberation on the part of individual women. The myth of the 'inherent maternal instinct' is used as the basis for women striving to become mothers; however, the necessity for social acceptance in keeping with the norms of the community is a more likely motivation (Raymond, 1993). This theory is supported by Wolf (2001), who suggests that mothering is not necessarily a natural transition, but is promoted in such a way to satisfy societal expectations and prevent women from exploring their own needs.

In light of the importance of the motherhood role in society, the infertile woman faces grave consequences at the prospect of remaining childless, or acquiring the label of barren or ‘non-mother’ (May, 1995). However, not being a mother is not necessarily viewed as devastating, nor does it always evoke feelings of unworthiness and failure. Women who seriously weigh up the pros and cons of motherhood versus non-motherhood may acknowledge that children are not without liability (Arendell, 2000; Forsyth, 1999; Letherby & Williams, 1999). Women rather than men are usually the primary caregivers of their offspring, and with this the inevitable responsibility of the many aspects of child rearing transpires. To not have children therefore frees women from what some may perceive as a burden, allowing them the independence to choose alternative paths in life (Connidis & McMullin, 1999).

Societal views, however, often portray those women who cannot have biological children as individuals to be pitied, thus reinforcing the ideal that motherhood is the pivotal reason for women’s existence, and that failure to successfully complete this task renders those individuals somewhat unfulfilled both personally and publicly. Letherby (1999) agrees, suggesting that “non-mothers often feel stigmatised and perceive that others view them as less than whole, pitiable and ‘desperate’ even though they often do not feel this way themselves”(p. 359). The infertile childless women who have been deprived of the right to choose whether they mother a child or not, and who subsequently do not perceive their supposed freedom as a benefit, nevertheless have to deal with feelings of failure and disappointment, without beginning to tackle the stigmatisation and negativity demonstrated by their social counterparts.

For women who undergo infertility treatment in an attempt to fit in to their widely accepted reproductive role, the focus is very narrowly centred on achieving a pregnancy, often resulting in an idealisation of the phenomenon of motherhood (Peters, 2003). Infertile women often welcome the prospect of experiencing weight gain, morning sickness, sleepless nights and changing nappies which are all usually considered negative aspects of pregnancy and new motherhood (Henry-Peiris, 1998; Peters, 2001). This idealisation of motherhood, and the lack of recognition of the hardships and labour actually faced in parenting a child may only serve to exacerbate the psychological turmoil experienced when the dream of impending motherhood fails to eventuate.

Nonetheless, women who access ART in pursuit of a biological child may be classed as deviant as they are seen to be meddling with nature (Arendell, 2000). If infertility treatment fails, the woman is forced to make decisions about whether or not to pursue motherhood by means of adoption or surrogacy, or remain a ‘non-mother’. However, these options may not always be considered a choice for women due to hurdles that must be overcome in order to pursue these other avenues.

Adopting a child is not necessarily a straightforward procedure. It is not simply a matter of registering for a baby, and then awaiting the arrival of that baby. It is an arduous process, in which potential adoptive parents must undergo a lengthy process of stringent physical, social, psychological and financial testing in order to determine their eligibility to parent an adopted child. They must basically open every aspect of their lives to the scrutiny of adoption agencies. As well as this, ‘open adoption’ policies, where access and information exchange for birth parents and their families must be adhered to (New South Wales [NSW] Department of

Community Services [DoCS], 2005; Victorian Government Department of Human Services [DHS], 2005) further complicate the adoption of a child. As adoption is no longer confidential, it is increasingly more difficult for adoptive parents to raise their adopted child as their own. Moreover, the adoptive process is often a very costly exercise and therefore eliminates adoption as a means of parenting for some members of society. Even if successful at adopting a child, there is no guarantee that women will be accepted as equal to their counterparts who have become biological mothers. This is evident in conclusions drawn by Letherby (1999) and Letherby and Williams (1999) that biological motherhood is considerably superior in the eyes of society than becoming a mother through an adoptive process.

Surrogacy is also promoted as a method of becoming a parent but is not without its dilemmas. Apart from the significant legal and ethical hurdles faced by all parties involved in a surrogacy agreement, surrogate mothers are not always readily available. As well as the considerations faced regarding choosing a surrogate mother, potential parents must also consider the possible outcome of the surrogate mother not wishing to give up the child she has carried to term. If in fact the ‘choice’ is made to remain childless or childfree, the woman may well face even more criticism due to her supposed lack of feeling and inferred self-centredness at not pursuing motherhood via adoption or surrogacy. Furthermore, a woman can be subjected to constant expectations of her willingness to care for other members of society’s children in order to compensate for not being able to have her own children (May, 1995).

The responsibilities and nurturing associated with biological motherhood commence at conception. The pregnant woman is expected to partake of

nutritious foods, eliminate alcohol from her diet and cease activities that may be perceived as being harmful to her unborn child (Wolf, 2001). The unforgettable body changes associated with pregnancy, and the physical and emotional process of labour and childbirth are events exclusive to those women who have earned the role of ‘biological mothering’. For involuntarily childless women, these events may possess a certain mystery and with it feelings of longing for something that they will never experience.

Motherhood as denoting maturity

Motherhood bestows positive identity on women, and is representational of a women’s transition to maturity (Woollett, 1991). The stigma of infertility encompasses a woman’s life in its entirety, with a sense of failure predominantly affecting what may be otherwise seen as great achievements (Whiteford & Gonzalez, 1995). According to these beliefs, infertile childless women will never see themselves as completing their developmental tasks because of a perception that reproduction is the only acceptable way of achieving adult status. This may lead to further stigmatisation and promotion of the detrimental psychological theories suggesting that infertile women lack the maturity to become mothers.

Jeffries and Konnert (2002) report that involuntarily childless women experience less psychological well-being than both voluntarily childless women and mothers. However, Jeffries and Konnert (2002) acknowledge that although these findings are supported by results from a similar study by Connidis and McMullin (1993), an earlier study by Beckman and Houser (1982) using a larger sample size found that childlessness in married women had no significant effects on well-being. Therefore, information regarding the impact that remaining involuntary childlessness has on the well-being of women remains inconclusive. Jeffries and

Konnert (2002) evaluated psychological well-being using ‘The Scales of Psychological Well-Being-Short Form’ which requires scoring on a Likert scale, thus limiting responses to set questions. Using such limited data to evaluate well-being, which is clearly subjective and requires an individualised response, is problematic.

Fatherhood, masculinity and infertility

While acknowledging the desire to have children as significantly greater in women than in men, Van Balen and Trimbos-Kemper (1995) affirm many similarities are evident. Edelmann, Humphrey and Owens (1994) also found many similarities with results from their survey, showing very little variance in the meaning of parenthood and reactions to male infertility between men and women.

Anthropological theories such as those highlighted by Franklin (1997) suggest that in ancient times sexual intercourse was either not associated with conception, or that ‘primitive promiscuity’ meant that paternity was indeterminable. In these cases then, biological fatherhood was of little consequence, and it was the fulfillment of social responsibilities that denoted who fathers were. However, the link between sexual intercourse and conception is now well known so fatherhood denotes more than social responsibilities. The additional factors attached to fatherhood are clearly evident in literature by Becker (2000), Humphrey, Humphrey and Ainsworth-Smith (1991) and Snowden, Mitchell and Snowden (1983), whose research illuminates many barriers to donor insemination. Men have grave reservations about the likelihood of another man being the biological parent to their prospective social child (Becker, 2000; Humphrey et al., 1991; Landau, 1998; Snowden et al., 1983).

A biological child is considered proof of manhood. Therefore, it follows that children conceived by donor insemination (DI) will not fully satisfy a man's goal of parenthood (Edelmann, et al., 1994). The conception may satisfy the social aspects of parenting but disclosure of the nature of a DI conception enhances the risk of further stigmatisation. The impact of male infertility and the absence of a biological child may depend on whether they perceive their infertility as being linked to a decrease in their masculinity. Edelmann et al. (1994) reports that men who do not consider that their infertility diminishes their masculinity usually show less infertility-related stress than those who perceive infertility as having a great impact on their manhood.

Irvine and Cawood (1996) report that male infertility has adverse effects on males' perceptions of their masculinity, with the majority of distress stemming from the loss of face as opposed to the loss of the chance of biological fatherhood. As biological parenthood is thought to serve as proof of masculinity and heterosexuality (Edelmann, et al., 1994), men who remain childless may reveal less about their emotional state to compensate for lacking this perceived proof. Connell (1995) reports multiple masculinities. Within these masculinities there exists a hierarchy. Not all men are equal with some men being subordinate and some are marginalised according to different characteristics, for example, class, preference of sexual partners and ethnicity. Furthermore, these masculinities are not fixed types but are situational, so a man may be subordinate in one situation but hold an authoritative position in another (Connell, 1995). Traditional hegemonic masculinity is associated with physical strength and dominance, an incessant interest in sex, and total emotional control, including the denial of vulnerability (Connell, 1995; Courtenay, 2000a; Gannon, Glover, & Abel, 2004).

Therefore, as Gannon et al. (2004) suggest, a man's masculine identity is threatened by infertility due to the perception that manliness is dependent on one's ability to father children.

Connell (1995) also highlights the close relationship between masculinity and a man's reproductive organs. This resonates with Elliot (1998) who affirms that men with fertility problems are likely to have concerns related to their sexuality, and whilst it cannot be assumed that fatherhood is any less important to men than to women, the outward reactions in men may suggest that they are less affected (Elliott, 1998). These obvious reactions in men, however, may be suggestive solely of an alternative way of coping rather than evidence of a lack of feeling. As Elliott argues:

A man's sense of masculinity, his ability to perform sexually and his capacity to be a biological father can be intricately entwined in some men; other men either separate these issues or do not draw their sense of identity and masculinity from their sexual performance or ability to procreate. (Elliott, 1998, p. 297)

Connections between gender and men's health have been drawn by Doyal (2001), who proposes that attempting to prove their masculinity may have adverse effects on their well-being. Although Doyal (2001) primarily discusses the physical injuries sustained by men in the pursuit of masculine recognition, men's psychological and emotional health may also suffer as they strive to mask emotions that could be interpreted as feminine characteristics.

Men as well as women must contend with the negativity of psychological theories surrounding infertility and childlessness. These theories promote ideas such as men being unwilling to give of themselves (Ovesey & Meyers, 1968), fear of success and possible retaliation (Friedman, 1973), and previous conditioning

whereby ejaculation only occurs with masturbatory stimuli (Dow, 1981). Apart from these stigmatising theories, men are subjected to taunts from others in society relating to issues of physical abnormalities that are supposedly negatively linked with their sexuality and masculinity. Infertile men report taunts such as ‘shooting blanks’, or allusions as to their possible sexual dysfunction (Irvine & Cawood, 1996).

Most literature addressing male infertility is quantitative in nature, using tools to measure stress levels and grief, and attests that men experience significantly less anxiety and grief reactions to both infertility and treatment failure (Beutel et al., 1999; Hjelmstedt, 1999; Mahlstedt, 1985; Stanton, Tennen, Affleck, & Mendola, 1991; Wright et al., 1991). However, some studies measuring psychological distress in infertile men have indicated that male infertility is indeed stressful and may have adverse effects on an individual’s psychological health (Band, Edelmann, Avery, & Brinsden, 1998; Glover, Gannon, Sherr, & Abel, 1996; Kedem, Mikulincer, & Nathanson, 1990). Nachtigall et al. (1992) found that men suffer a similar intensity of distress to women only when a male problem is identified whilst women experience negative emotional outcomes irrespective of which partner has the reproductive impairment. The ways in which men cope with illness, and the stereotypes that encourage them to react in specified ways as highlighted by Moynihan (1998), suggest that maintaining a ‘stiff upper lip’ in times of grief/hardship is somehow perceived as a way of maintaining their masculinity or masculine identities. Moynihan (1998) also demonstrates that quantitative data collection methods fail to allow individual expression. Moynihan (1998) concurs with Riessman (1990) regarding interviewing being a more enriching and accurate way of exploring men’s experiences.

Men are rarely seen expressing emotional pain publicly. This may be explained in part, Courtenay (2000b) suggests, by the fact that men may not consider the public showing of such emotions appropriate. Biddulph (2002) concurs, stating that men tend to repress their emotions as proof of masculinity and heterosexuality and may use a ‘macho’ facade and carefree mien to avoid being ridiculed. Croyle and Waltz (2002) suggest that rather than the suppression of emotion, a lack of emotional awareness results in emotions not being displayed or addressed. Knowledge of health beliefs and behaviours in infertile men is of particular importance in light of the fact that men’s stoical manner may have a potentially negative impact on their health (Courtenay, 2000a; Moynihan, 1998).

The results from a postal survey distributed to 205 couples with male factor infertility suggest that women experience greater distress than men in relation to donor insemination (Owens, Edelmann & Humphrey, 1993). However, Dhillon, Cumming, and Cumming (2000) suggest that women are more likely than men to be more open in expressing their feelings. Most research on men affected by infertility (such as that by Forsyth, 1999; Imeson & McMurray, 1996; Milne, 1988; Nachtigall et al., 1992; Throsby, 2004) has to date represented the man within a couple dyad so the males have had a limited voice when it comes to their individual experiences. Research dedicated to highlighting men’s experiences of infertility (see Webb & Daniluk 1999) interviewed men who had already become fathers either by adoption or donor insemination, whereas this research will gather individual stories from men who remain childless.

Men coping with ART

Jarow et al. (2002) suggest best practice policies for male infertility, including physical causes, possible outcomes, how to screen for male infertility, and various

techniques to reverse problems. However, Jarow et al. (2002) fail to address the psychological effects of infertility and treatment for infertility in policies that advocate best practice, thus exemplifying common attitudes among health professionals toward men's emotional status and requirements.

Carmeli and Birenbaum-Carmeli (1994) highlight the feelings of embarrassment experienced by men in producing a semen sample. The stress involved in producing a semen sample is documented as being contributed to by concerns about their virility, their responsibility to their partner to produce a sample, the assisted reproductive cycle being dependent on the sample being obtained and the loss of face before health professionals if a sample is unable to be supplied (Carmeli & Birenbaum-Carmeli, 1994; Kedem et al., 1990; Nachtingall et al., 1992; Throsby & Gill, 2004). Further to this, case studies by Emery, Senn, Wisard, and Germond (2004) illustrate the negative impact on men and their partners in the event of ejaculation failure on the day oocytes are retrieved, resulting in relationship crises and in one case psychiatric hospitalisation of the man.

Studies highlighting psychological and psychosocial gender differences in infertile couples utilise various tools. However, utilising the same instruments to collect quantitative data from both men and women may result in important differences being missed (Wright et al., 1991). As men and women have very different roles in ART, questions relating to specific treatments may not be relevant for both members of a couple. For example, if men are asked 'Do you find treatment physically tiring?' they will undoubtedly have very different answers from women, as they do not go through the same treatments. This is not to say that they do not find other aspects of the treatment stressful. If in fact

quantitative studies asked the same questions of both men and women, conclusions drawn may be inaccurate. The conclusion in many studies that men suffer less infertility-related stress than women may reflect the questions put to them rather than an accurate account of their stress levels.

Dhillon et al. (2000) measured stress in 30 fertile men with pregnant wives and compared them to 30 euspermic (normal sperm count, categorized as unexplained infertility), and 30 oligoasthenospermic (low sperm count, thus categorized as infertile) men whose partners were undergoing ovulation stimulation. The sample groups compared in the study by Dhillon et al. are totally diverse but the authors conclude that coping in all three groups of men was similar, suggesting that men's psychological adjustment to their own infertility and unexplained infertility is healthy. However, just because men who participated in the above study gave answers that were quantifiably comparable and similar does not mean that infertile men 'cope' with infertility treatment similarly to men who have unexplained infertility.

In contrast with findings by Dhillon et al. (2000), Band et al. (1998), who investigated correlates of distress in men with male factor infertility, found that male-related infertility is perceived as stressful for those concerned and can be associated with a greater risk of psychopathology. Furthermore, the social construction of masculinity and fatherhood renders void the use of psychometrically proven tools used by many (such as Band et al., 1998; Beutel et al., 1999; Dhillon et al., 2000; Fassino, Piero, Boggio, Piccioni, & Garzaro, 2002; Hjelmstedt, 1999) for the purpose of measuring stress associated with men's infertility. Greil (1997) agrees, arguing that more attention should be afforded to the way the experience of infertility is influenced by social constructions.

Dhillon et al. (2000) suggest that finding a ‘clear lack of distress recorded on any of the psychological measures’ (p.702) may point to men not being adversely affected by their infertility, but the finding may also mean that questionnaires do not provide an accurate account of men’s experiences. The latter view is supported by Riessman (1990), who notes that the emotional status of men is more accurately portrayed in interview data than in quantifiable measures used in most research. Quantitative methods of data collection leave little or no room for individual experience or depth of experience. Within an individual’s language there is a distinct difference between description and interpretation. Individuals may describe how they feel or how they are coping and relay information to the listener in positive terms, but the underlying tone of the description may have very negative connotations. Riessman (1990) acknowledges that quantitative methodologies can be problematic as they do not allow comprehensive answers and therefore fail to address the depths of individual experience. Research by Webb and Daniluk (1999) disputes research that suggests that men are not distressed by their infertility by providing qualitative findings indicating they suffer significant emotional pain. Without further research that reflects men’s experiences, professional knowledge will remain limited, thus precluding appropriate delivery of care and support.

Carmeli and Birenbaum Carmeli (1994) claim that the inequality in assisted reproductive treatment has led to three-quarters of female infertility being able to be resolved but only one third of male infertility likely to be helped (p. 665). This inequality in healthcare holds consequences not only for the infertile men in question but also for their female partners. If in fact women do suffer greater distress than men when faced with the prospect of alternate methods of parenting

other than the norms accepted by society, once again women are gravely affected by the relative lack of research and treatment into male infertility.

Carmeli and Birenbaum-Carmeli (1994) stress that women are the focus of medical attention. Men were absent from daily clinic visits, and additional financial burdens were placed on couples due to the necessity of women giving up work or cutting down their working hours in order to comply with enforced timeframes for procedures. Men were sometimes excluded by clinics from being present at various procedures performed on their partners, for example vaginal examinations and inseminations (Carmeli & Birenbaum-Carmeli, 1994). This enforced absence from procedures that an infertile man may feel responsible for putting his partner through raises questions regarding the effects on both the man's psychological health and subsequently the relationship with his partner. The outcome on the woman of not having the support of her partner throughout such procedures has not been explored in relation to the mutual relationship of the couple.

Stigmatisation: imagined or real?

Infertile individuals have long been the object of stigmatisation, with the affected individual's (or couple's) physical, emotional, social, spiritual and psychological status questioned due to their inability to reproduce (Anleu, 1993; Miall, 1986; Schaffer & Diamond, 1993; Whiteford & Gonzalez, 1995). Stigma is the term used to refer to a deeply discrediting attribute that disqualifies an individual from total social acceptance (Goffman, 1963). It is generally assumed that stigmatisation is directly related to low self-esteem in the stigmatised individual. This belief is based on the theory that people construct a concept of self, based on

the responses received by others (Crocker, 1999). Crocker (1999) argues that in the stigmatised individual, low self-esteem is not a blanket characteristic but a phenomenon that arises in particular situations. Understandings or perceptions brought to a situation by an individual may lead to decreased self-esteem in that situation, but not necessarily in all situations (Crocker, 1999). A childless couple may feel inadequate or have low self-esteem in the presence of those who they perceive will see them as inferior or those who have expectations of them to reproduce, but they may feel valued in the presence of others without the same expectations. As Greil points out:

Infertility is a disability insofar as it involves long-term limitations on an individual's ability to perform social roles and normal daily activities as a result of a physical impairment. (Greil, 1991, p. 17)

In Greil's (1991) study, couples interviewed had not divulged their infertility to neighbours and acquaintances prior to adopting children. As most of the participants had adopted or become pregnant prior to the interview, the author proposes that infertile couples were more likely to talk about their experiences of childlessness now that they were no longer experiencing it (Greil, 1991). This alludes to the couples' perceiving their stigma related to infertility as being resolved after they have adopted a child, as they have remedied one of their stigmatising attributes, that is, of being childless.

Infertile childless women have been studied regarding their disclosure practices when asked about their childlessness. Among strategies used, childless couples employed deception by not revealing which of the couple was infertile. This was perceived by them to prevent blame being attributed to either one of the couple, thus preventing further stigmatisation (Miall, 1986). Commonly, relevant

literature reveals that involuntarily childless couples perceive themselves as deviant and therefore expect social attitudes to reflect a similar verdict. Van Balen and Trimbos-Kemper (1995) refer to identity being the primary motive for childless women to become mothers, with this feminine identity being largely socially constructed around the importance of motherhood. Furthermore, women who are childless and access ART have a strong identification with feminine sex-roles (Colpin, DeMunter & Vandemeulebroecke, 1998). This may contribute to perceptions by involuntary childless women that they will be stigmatised for failing to fulfill their socially expected role of motherhood. Using Goffman's (1963) concept, Greil (1991) refers to a 'spoiled identity', once again suggesting that women are more affected by a sense of loss and failure than men if their quest for biological parenthood is not realised. If men really are not as affected by infertility, then perhaps the concept of 'spoiled identity' is due to the constructs of society and the physical phenomenon of pregnancy.

Greil (1991) makes the assumption, based on the physical rigours of infertility treatment, that treatment takes a central place in the couple's lives, more so for wives than husbands. It would be difficult to argue with this assumption if evaluating time and energy spent on a physical level. However, it may be rather presumptuous to discount the emotional, psychological, financial and social effects that infertility treatment places on male partners also. Although suggesting that men are less affected by infertility in terms of stigma felt, Greil (1991) concedes that these findings were revealed in a study where husbands were interviewed by male researchers, and there may have been reluctance on the part of the participant to divulge feelings of failure and inadequacy to one of their own

sex. Alternately, this reluctance or perhaps even inability to share feelings may extend to individuals of either sex.

Theories which suggest that women feel conflict or ambivalence about motherhood are unable to conceive or unable to carry a child as they have hostile mucous or an incompetent cervix, all lead to the stigmatisation or at least the perceived stigmatisation of infertile couples. Schaffer and Diamond (1993) acknowledge that infertile couples have been pathologised and stigmatised although infertility is often referred to as the ‘secret stigma’ as it is not outwardly apparent (Whiteford & Gonzalez, 1995). This resonates with Goffman’s (1963) theory that suggests that there are two types of stigmatised individuals: those who are discredited, as their stigma is immediately evident, and those who are discreditable, in that their stigma is not immediately perceivable. Goffman acknowledges that discreditable individuals may need to constantly work at concealing their stigmatising attribute or risk being discredited. Whilst infertility may be easily concealed, childlessness is apparent, particularly in couples that have committed themselves to marriage and have not yet reproduced. It has been suggested that now cohabitation without marriage is more acceptable, marriage remains more closely associated with the desire and expectation to have children (Burgoyne, 1987). Infertility also becomes apparent if it is known that the couple have accessed ART.

Perception of stigma differs depending on the perceived controllability of its origin (Crocker, 1999). Psychological theories insinuating that infertility is a product of immaturity, and comments made to many infertile individuals such as ‘you just need a holiday’, or inferences and advice regarding certain positions that should be maintained during and after intercourse, denote that the infertile have

significant control over their state of childlessness, resulting in increased stigmatisation (Daniluk, 1999; Miall, 1986). Further fuelling this culture of blaming, Biddulph (2002) refers to specific psychological work he has performed with women and claims ‘I have known fertility problems to disappear through this work – as if a woman’s body would not bear a child until her mind knew it could and would protect that child’ (p. 74). This comment, apart from negating the presence of unwanted and abused children worldwide, unjustifiably represents infertility as a psychological problem, and furthermore positions women as being in control of their own fertility. Literature such as this serves to consolidate traditional views, pointed out by Steinberg (1990), that women are held responsible for ‘barrenness’ irrespective of the physiological origins of infertility.

Women to blame

Reasons cited for a psychological cause to infertility are manifold. Infertile women in particular have often been accused of having unresolved issues regarding their sexuality, femininity and a lack of desire to have a child (Apfel & Keylor, 2002; Forrest & Gilbert, 1992; Zucker, 1999). May (1995) affirms that in the past young girls were discouraged from studying due to a myth that educated women did not reproduce as education destroyed a woman’s reproductive organs. Miall (1994) argues that adoption is often seen as a ‘cure’ for infertility, and this belief suggests that the inability to conceive is psychological in origin. Hennelly, Harrison, Kelly, Jacob and Barrett (2000) concur with the psychological theory, stating that the most likely cause of spontaneous conception after a successful ART treatment cycle is the ‘relief from stress that undoubtedly occurs after an infertile couple finally has a child’ (p. 777).

Assumptions made concerning women's physical status are also aimed at provoking guilt in women. Accusations regarding a woman's sexual health and promiscuity are commonplace with allusions and allegations of sexually transmitted diseases, or indeed their decision to use contraception at some stage of their lives, being responsible for their infertility (Sandelowski, 1986b; Shattuck & Schwarz, 1991). These insinuations along with others that claim that women have 'hostile mucus', 'hostile uterine environments' and 'allergic reactions' to sperm all create and reinforce a sense of blame directed at the women (Rowland, 1992;).

Along with the concept of infertility comes a variety of subtle issues, not least of which highlights the inequality of terminology – and attitudes in general – between male and female infertility. Infertile women bear the brunt of societal blame and negativity surrounding their inability to procreate, while men are rarely addressed regarding their reproductive capabilities. Riessman (2000) informs us that Indian women are subjected to public ridicule if they remain childless, irrespective of the fact that their husbands may be infertile. In addition, certain Eastern cultures believe that by not having children, couples, or women in particular, are shirking their responsibility for reproduction. As a woman's existence is thought to be primarily for the purpose of procreation, infertile childless women or indeed fertile women with infertile partners may be subjected to abandonment, abuse and even murder in some cultures (Jacobsen, 1993; Lee & Kuo, 2000).

Men and infertility

Infertile men do not receive similar levels of attention, partly due to the inequality of culpability and non-recognition of the fact that male-related infertility accounts for a large portion of infertility in childless couples. Therefore, it stands to reason

that there will there be less societal support available for infertile men, as males are not expected to have difficulty in reproducing. It remains unacceptable among the male population to have difficulty with procreation, with stigmas attached such as a loss of masculinity and loss of worthiness to be male. Biological parenting is often proof of heterosexuality for men, and the inability to fulfill traditional male roles, due to the failure to cause a conception, may negatively impact on a male's masculinity (Hurst, Dye, Rutherford, & Oudit, 1999; Wirtberg, 1999).

Whilst promoting stringent guidelines on who is 'worthy' of assisted reproductive treatment Jansen (1997) proposes that if the male of the couple is infertile, then it is more difficult for him than the woman because 'in principle, his wife could leave him because of his sterility to find another partner, and he would then find it very difficult with honesty to form a new relationship in which having children was contemplated' (p. 321). What Jansen (1997) fails to consider, however, is that infertile women may experience the same or similar difficulties.

Couples and infertility

Those who have children remain largely unaware of the impact infertility has on couples who are affected by it, and lay the blame at the feet of the childless couple, sometimes under the guise of being supportive. For example, unhelpful comments such as those quoted throughout Miall's (1994) study, alluding to the fact that the infertile couple just need to relax, change their diet or adopt a child, show a general lack of education and understanding about the causes and consequences of infertility.

Not having biological children also signifies the end of the family line for infertile couples. Studies such as those by Rowland (1998) accentuate the social importance of having children, particularly in an aging population, by concluding that childless women are more likely to be institutionalised in later life than those who have children. This is supported by studies that report that remaining childless significantly increases the risk of social isolation and nursing home admission in later life (Bachrach, 1980; Freedman, 1996).

The marital relationship comes under scrutiny in the absence of children, with people deeming childless marriages unsuccessful, while referring to children being the focus of successful marriages, even in the light of research showing a decline in marital happiness coinciding with the introduction of children (Van Laningham, Johnson, & Amato, 2001). Edelmann et al. (1994) agree, revealing that some studies imply that the marital relationships of infertile couples are generally stable and well adjusted (p. 292). McNaughton-Cassill et al. (2000), however, argue that infertile couples experience stress that can result in negative outcomes that can lead to relationship difficulties and divorce.

Religion has long been a guilt-provoking phenomenon particularly for those who are considered outside the norms of their religious group. Infertile childless couples definitely live outside what is considered the religious norm as in the Bible God commands, ‘Be fruitful and multiply’.⁵ Along with the inability of the infertile to comply with this request or order, there are also consequences attached to the failure to procreate. These stem from the stigmatisation that originates in

⁵ Genesis 1: 22

such material as ‘For the family of the ungodly shall be barren’.⁶ This scripture implies that a community not being barren is a reward and that bearing children is repayment for doing God’s work. The message is then clear that ‘barrenness’ is a punishment for those who are disrespectful and negligent in their religious duties or obligations. The importance of reproduction for those with high religious affiliation could be illustrated in the Australian Bureau of Statistics (ABS) (1999), which shows that the level of childlessness is significantly lower in women with a higher degree of religious faith. This raises questions regarding the possible religious affiliations for those who remain childless.

May (1995) states that in the past childless couples ‘had to prove themselves worthy in ways that their fertile neighbors [sic] did not’ (p. 30). This proof of worthiness came in the form of taking others into their house or caring for many others in the community. As mortality rates were higher, there were more children orphaned. The childless were expected to take these children into their homes and treat them as they would their own family. Today infertile couples are encouraged to become parents in any way possible, with the societal presumption that remaining childless is the most undesirable alternative (te Velde & Cohlen, 1999). Options that are often taken by childless couples in an attempt to fulfill their societal obligation include ART, fostering, national and international adoption or looking after the children of friends or family.

Negative language

Language has the potential to convey meanings that may be insensitive and hurtful to groups and/or individuals. People communicate their feelings and ideals

⁶ Job 15: 34

in ways that often convey a partially subconscious meaning. This often unwittingly results in dialogue that is detrimental to relationships of all types. For those who have been, or remain the object of stigmatisation, sensitivity to negative language is high.

Infertility is a word deeply ingrained in the constructs of negativism. Synonyms of infertile and infertility include unproductiveness, unfruitfulness, sterile, dried up, barren and emptiness (Butterfield, 2003; Kipfer, 2006), all expressing implied disapproval. Negative discourse has evolved over the years, from the primary blame placed upon women for their ‘barrenness’ in biblical days, to their recent non-compliance in the reproductive process by providing a less than optimum environment for a man’s sperm, in the form of theories about ‘hostile cervical mucus’, or an ‘incompetent cervix or uterus’ (Daniluk, 1999).

Men have also been subjected to ridicule if their infertility has been disclosed. In a study of infertile South African men by Dyer, Abrahams, Mokoena, and van der Spuy (2004), participants reported “being called names such as ‘tjoekie’ (failure) or ‘incabi’ (castrated cow) and comments would be made such as ‘bad swimmers’, ‘shooting blanks’ and ‘water penis’” (p. 964). As well as name calling, participants of the study by Dyer et al. (2004) were often taunted by other men suggesting that perhaps they would be able to impregnate their wives for them.

This derogatory rhetoric extends to ART services. Terminology used in professional ART forums and literature includes ‘hatching’, (a term used to describe a stage of embryonic development) (Edi-Osagie, Hooper, McGinlay, & Seif, 2005), and ‘harvesting’ of ova and sperm (Oates et al., 1996), (used instead

of ‘collection’ or ‘retrieval’). In light of this agricultural choice of language, it is hardly surprising, as highlighted by Rowland (1992), that IVF has often been referred to as ‘baby farming’.

Those who access ART are often portrayed as ‘desperate’ (Franklin, 1990) and if treatment does not result in the birth of a child they are represented as ‘failures’ of reproduction. *Childless* by definition holds negative connotations with the suffix *less* meaning without, lacking or being unable to do something (Butterfield, 2003). Wearing the labels of such negative language deems those without children as ‘less than normal’ and therefore subject to stigmatisation.

Medicalisation and stigma

Anleu (1993) proposes that involuntary childlessness is seen as an involuntary deviance. However, with reproductive technology becoming increasingly accepted as a compulsory path for those with infertility problems, the refusal to submit to these procedures is not acceptable. Infertile couples are obliged to seek medical treatment for the ‘disease’ of infertility in order to prove to other members of society that they have explored every possible avenue to ensure biological parenthood. Failure to participate in the offered treatment now represents a deviation from the medicalised norms of society, increasing the severity of stigmatisation.

Voluntary childlessness is distinct from involuntary childlessness in terms of stigmatisation. The voluntary decision to not procreate denotes a conscious non-conformity to social norms that is viewed negatively by most members of society (Anleu, 1993). Involuntarily childless women, however, are thought to internalise negative perceptions of themselves, viewing their ‘failure’ of reproduction as their

own inadequacy, which may differ significantly from the way in which they are perceived by people (Anleu, 1993). However, the way in which societal members view involuntarily childlessness does not necessarily mean that this is a positive thing. If pity and sympathy are offered, this can be equally stigmatising and damaging to one's self-esteem. Weiner, Perry, and Magnusson (1988) suggest that pity is offered to those who can attribute their stigma as out of their control. This may be the case in some instances of infertility and involuntary childlessness. However, infertility is frequently attributed to things that are perceived to be within a woman's control (Sandelowski, 1990). Infertility due to delayed childbearing, sexually transmitted diseases, contraception and work environments may evoke blame and condemnation towards infertile women due to the perception that this 'disease' or 'disability' was of the individual's own making (Sandelowski, 1990).

According to Greil, Leitko and Porter (1988), the expectation is lower for men to be fathers than of women to fulfill the role of motherhood, and therefore the identity of infertile childless men is less likely to be 'spoiled' or affected in terms of role failure. Women are referred to as being more stigmatised than men for their infertility and childlessness. Women have been noted to carry a 'courtesy stigma', based on their partner's infertility (Greil, et al., 1988; Miall, 1986). Women with no fertility problems of their own refer to themselves as being infertile when in fact their partners have the reproductive impairment (Anleu, 1993; Greil, 1991). Miall (1994) suggests this may be due to male infertility being considered as more stigmatising than female infertility.

Infertility as a disability

Infertility and involuntary childlessness are likened to having a chronic illness, although unlike disabilities such as paraplegia or blindness it is invisible (Goffman, 1963; Greil, 1991; Joachim & Acorn, 2000). Authors such as Miall (1986) suggest that involuntary childlessness is considered a form of disability, where infertile women view their infertility as a negative predicament, a failure of sorts and perceive that others disapprove of their inability to procreate. The perception held by infertile women that infertility is a negative affliction is substantially supported by literature highlighting the secrecy associated with any infertility treatment (Miall, 1986; Peters, 2003). As in many other studies, women in Peters' (2003) study had difficulty disclosing their infertility to family and friends. Miall (1986) suggests that women have more difficulty disclosing if male infertility is the predominant factor as male infertility is so much more discrediting to their partners' masculinity.

The infertile couple and treatment failure

Although there are those who advocate treating the couple as a unit (Greil, et al., 1988; Kuczynski, 1989; Menning, 1980), literature addressing the effects that infertility treatment and childlessness has on couples has so far primarily involved shared interviews with one partner being the major spokesperson (Daniluk, 2001; Forsyth, 1999; Imeson & McMurray, 1996; Milne, 1988; Nachtigall et al., 1992; Throsby, 2002). When considering this approach, issues regarding how comfortable each would be with telling their complete story in the presence of their partner need to be considered. Couples may withhold information specific to their story in order to protect a partner from emotional hurt or simply because they do not feel comfortable or safe discussing certain issues in the presence of

their partner. Literature on couples' counselling acknowledges that the dynamics of the couple need to be explored simultaneously with the individuals, taking into account both historical and current influences in their relationship (Weeks & Treat, 1992). Sandelowski (1994) agrees, stating: "The couple-is-the-patient focus advocated for in infertility practice may mask important differences between women and men" (p. 750).

It is therefore important to consider the individuals in the partnership, acknowledging both gender and outside influences that may impact either directly or indirectly on the couple differently and together. To address the dynamics of a couple without in-depth individual consideration, given the complexity of the experiences of treatment and treatment failure, appears to skim the surface of this very complex phenomenon. While infertility is usually a shared phenomenon between two people of the opposite sex, the process of caring for the infertile individual is paramount to the appropriate delivery of care, whilst acknowledging and taking into account the potential effects of treatment failure and subsequent childlessness on both partners.

Representations of 'success' in ART

The link between infertility and childlessness is highlighted by statistics that show the possibility of achieving a viable pregnancy through assisted conception is as low as 15.9% per embryo transfer (ET) (Hurst & Lancaster, 2001). Viability is, of course, not to be confused with a successful pregnancy – that is, one that results in the birth of a living, healthy infant. Hurst and Lancaster (2001) define a viable pregnancy as being a pregnancy of at least 20 weeks gestation (p. 71). However, the chances of achieving a biochemical pregnancy (i.e., a pregnancy evidenced only by an increase in serum β human chorionic gonadotrophin [β hCG]) (Hurst &

Lancaster, 2001) or a clinical pregnancy (which is evidenced by visualisation of a gestational sac on ultrasound and includes ectopic pregnancies, blighted ovum and spontaneous abortions), (Bryant, Sullivan, & Dean, 2004) are much higher than the likelihood of maintaining a pregnancy until 20 weeks gestation. All of the above definitions of pregnancy can be used to promote various clinics and procedures as successful at curing infertility.

Viable pregnancies do not necessarily result in live births, and in 1999, the number of live births recorded from assisted conception was 76.6% of the 15.9% of viable pregnancies (Hurst & Lancaster, 2001). This brought the rate of live births down to approximately 12% per ET. However, with the definition of live birth being an ‘Infant with signs of life after pregnancy of at least 20 weeks’ gestation’ (Hurst & Lancaster, 2001, p. 70), the number of live, healthy, infants that result from assisted conception techniques may be very much lower.

More recent statistics presented by Dean and Sullivan (2003) for the year 2000 outcomes allude to a much increased success rate for ART. Figures in their report suggest that ART programmes have a 21.2% clinical pregnancy rate per ET. However, many of these include spontaneous abortions, blighted ovum and ectopic pregnancies (Dean & Sullivan, 2003). These bring the viable pregnancy rate down to 17.9%. The number of foetal deaths brings the success rate down to 17% and with a further 1% of neonatal deaths, which is infants alive at birth but dying within 28 days of birth, the success rate, or the chance of actually having a ‘take home’ baby, drop to 16%. Figures stating complications due to preterm births (which occur in about 25% of cases) are not included in this report (Dean & Sullivan, 2003).

There is further embellishment of favourable outcomes for ART in the report by Dean and Sullivan (2003) with twins who are alive at birth being counted as two successes, but in the case where one is stillborn and the other survives, the live birth is the only one counted. Additionally, in light of information revealed by Hansen, Kurinczuk, Bower, and Webb (2002) that major birth defects are twice as prevalent in IVF babies when compared with those naturally conceived, and with the increased incidence of multiple births resulting in an increased likelihood of premature births and related complications including neonatal death (Armour & Callister, 2005), the way in which the term ‘success’ is used becomes problematic.

What is clear is that because of the varied definitions of success used by clinics, the potential for a misrepresentation of statistics is increased. The range of words used to denote varying degrees of success may well confuse consumers, who may consider that ‘success’ means the chance to become parents to their biological child. Furthermore, Greil (1991) highlights that very few couples are ever told that they have no chance of becoming biological parents, which may contribute to feelings of ambiguity. The hope that this lack of finality instils in infertile couples may hinder their progression by delaying adoption of other children or by putting their life on hold.

Grief and loss in infertility

Infertility is recognized as a life crisis (Devine, 2003; Schoener & Krysa, 1996) and both infertility and related treatments often cause feelings of loss and grief in infertile couples (Freda, Devine, & Semelsberger, 2003; Sherrod, 2004). Webb and Daniluk (1999) describe a sense of profound grief and loss experienced by participant men surrounding their loss of fertility, genetic continuity, masculinity,

control and meaning in life. Similarly, in another phenomenological study Johansson and Berg (2005) found that central to the lives of eight women participants was ‘life-grief’, which refers to the grief of not reproducing, of remaining childless and the inability to confirm their marital relationships through parenthood.

Apart from the grief experienced due to the loss of fertility, infertile couples who pursue ART are often required to cope with further loss in relinquishing reproductive control to ART services (Peters, 2001). ART services dictate the timeliness of both voluntary functions (e.g., by directing couples when to have and not have intercourse) and involuntary functions (e.g., by overriding the normal ovulatory response) associated with the reproductive system.

Grief may also be experienced by couples who access ART with each failed ART cycle due to the perception that each embryo transferred is a potential baby (Peters, 2001). Furthermore, those who do ‘succeed’ at establishing a pregnancy with ART assistance but are unable to maintain this pregnancy (e.g., in the case of miscarriage or ectopic pregnancy) are documented as experiencing intense grief due to their loss (Freda et al., 2003; Peters, 2001). Johansson and Berg (2005) acknowledge that implications for future research include men’s experiences of childlessness and those who are approaching the age of when they might have been grandparents. Furthermore, the paucity of literature available on grief related to these multiple losses warrants additional research.

Alternative means of parenting

Infertile couples who have had no success with ART are expected by some members of society to attempt to achieve parental status by other means such as

surrogacy or adoption. May (1995) agrees that society cares “more about each other’s reproductive behaviour than about each other’s children” (p.259). It may be then more acceptable for couples to adopt children automatically to fill a social void rather than to live without children and be shunned by their community. May (1995) highlighted the differences between biological and social parenting when interviewing women who were ashamed of the fact that their feelings for their adopted children were not as strong as for their biological children. Mather (1999) states “Doctors continue to recommend adoption as a solution to infertility without appreciating that couples might not succeed in adopting the baby they desperately want, or the magnitude of the task that could face them with the adoption of an older child” (p.492). With this in mind, childless couples may not feel they have a right to cease assisted reproductive treatment and remain childless, without having to contend with the negative attitudes of some members of society.

Biological parenting cannot be paralleled to either adoption or surrogacy. The relationship between parents and their biological child begins at conception, and as a result of reproductive technologies such as ultrasonography, awareness of the foetus and the recognition of it as a baby now occurs much earlier in pregnancy (Sandelowski, 1988). Even without the use of technology it is argued by Wynn (2002) that the bond between mother and infant commences much earlier than birth. This time is commonly perceived as a time of great joy and excitement at the prospect of creating a new being, and ideally, a pregnant woman is nurtured by her partner and family as well as by society in general for the term of her pregnancy. Alternatively, a woman who adopts a child is not always given this nurturing and positive attention (Daniluk, 1996; Letherby, 1999; May, 1995).

The study by Daniluk (1996) suggests that for participants adoption cannot be a substitute for a biological child, the participants conveying that the reality of their childlessness left “an emptiness that could never be fully fulfilled even if they were fortunate enough to become parents through adoption” (p. 4). Although women are encouraged to become mothers by any means available, social motherhood takes second place to biological motherhood, with the role of an adoptive mother being stigmatised because of the prevailing belief that dictates the normalcy of family as those with genetic ties (Letherby, 1999; Wegar, 2000).

In recent years there have been progressively fewer children available for adoption in Australia due to increased social and financial support for single parents and working mothers. The latest Australian statistics show that in 1971-72 there were 9798 children available for adoption, with very few of these being from overseas countries, decreasing to 668 available in 1995-96 with the majority of these being overseas adoptions (ABS, 1998). Apart from this severe decline in the number of children available for adoption and the complex social and psychological issues associated with contemplating surrogacy, adoption and surrogacy have associated legal issues and screening processes in place that eventually determine the worthiness and appropriateness of the applicants to become parents (May, 1995).

Infertility, childlessness and relationships

Inferences are made that childbearing is positively associated with the quality of the marital relationship and negatively related to proneness to divorce (Heaton, Jacobson & Holland, 1999). Most couples commence a relationship and plan their lives with the assumption that they will have children, and that they are fertile. There is such an emphasis on contraception prior to a couple being married and

financially secure, when couples must avoid pregnancy. Therefore it is easy for them to presume that pregnancy will happen automatically when contraception is removed from the equation (Becker, 1990). With continual attempts at pregnancy, the most intimate parts of the relationship may become a chore. Daniluk (1999) suggests that the structure enforced on a couple's sexual relationship by infertility treatment results in the transformation of love making to baby making. The adverse affects of treatment on a couple's sexual function is often briefly mentioned but remains relatively poorly addressed in the literature and possibly rarely addressed at a patient level. The possibility that this intimate act between partners may become mundane and fraught with tension contributes to reported detrimental consequences for the couple's relationship.

Women who are trying to conceive are depicted as immediately thinking of whether they are ovulating and when they last menstruated, and as becoming ultra-sensitive to any body changes, whereas men are portrayed as more relaxed, and less preoccupied with immediate pregnancy (Becker, 1990). What Becker (1990) is suggesting, then, is that couples are on different wavelengths, have different attitudes. This makes it difficult to understand the dynamics of the couple, with one being concerned and the other relatively untroubled by the same situation. This difference in the way of thinking about such a sensitive and vital issue has a negative effect on their relationship.

Research that studies the relationships of infertile couples presents diverse findings. Peterson, Newton and Rosen (2003) attest to infertile couples reporting high levels of marital satisfaction. Greil (1997) agrees affirming that compared to fertile couples, marital satisfaction is higher in infertile couples. However Leiblum, Aviv and Hamer (1998) found that infertile childless women regard

infertility as having a significantly negative impact on their marriages. Further studies by Benazon, Wright and Sabourin (1992) and Berg and Wilson (1991) confirm that as treatment for infertility progressed, marital distress increased, with greatest levels of marital distress experienced by couples who did not conceive. As findings from these quantitative studies are inconsistent, further research regarding the impact of infertility and childlessness has on couples' relationships is required. Moreover, research using qualitative methods has the capacity to provide a more in-depth view of this phenomenon.

Conclusion

The importance placed on procreation, and the negative connotations that infertility holds for both men and women is evident in past and current literature. Furthermore, the negative impact that various infertility treatments can have on couples' lives is illuminated. What is not addressed adequately, however, is the impact of treatment failure on both members of a couple, taking into consideration both individual and shared experiences. It is clear that with most literature using quantitative methodologies, infertile childless couples are not able to voice their responses, suggesting an oppressive silencing of their opinion. A qualitative methodology with feminist grounding is chosen for the purpose of this research in an attempt to illuminate dominant issues within the stories of those who remain childless.

Due to the paucity of literature available that acknowledges individuality as well as the shared experience of couples for whom ART has failed, health professionals may encounter some difficulty in providing this population with appropriate support. A review of the literature pertaining to both infertility and

involuntary childlessness found deficiencies in areas of supportive and realistic strategies for supporting and assisting these couples. Van Manen (1990, p.62) acknowledges, “We gather other people’s experiences because they allow us to become more experienced ourselves”. The purpose of this research is to inform nursing knowledge by highlighting men’s and women’s individual as well as shared experiences. As detailed in the following chapter, this is achieved by using a qualitative methodology informed by feminist perspectives and by collecting the individual stories of members of couples who have made the decision to remain childless after undergoing treatment for infertility.

Chapter Three

VALUING THE STORYTELLER

*We need to always remember
 That more than the words we speak
 It's the gift of someone who listens
 That most of us desperately seek.
 (Author Unknown, 2006)⁷*

Introduction

From the previous chapter it is evident that much research literature on infertile couples remains trapped in a quantitative approach that seeks to find causes for infertility or failure to conceive in the psychological characteristics of the couples and the individuals involved. Few studies account for the structures of society, such as familial ideologies, on the couples undergoing ART or examine what impact this may have when treatment fails. Existing qualitative studies suggest there is more to discover about the 75% of couples who do not conceive using this technique. As structural effects loom large in the discussion so far, the methodology for this study adopts a feminist perspective in order to encourage a fuller expression of the experiences of treatment and its consequences for couples who choose to not follow other remaining options for becoming a family.

Feminist methodologies are characterised by a stance that works *with* women rather than *on* them. These same methodologies have been used effectively to

⁷ Hollister, D (Ed) (2006) *The gift of someone who listens*. Retrieved April 17 2006 <http://www.bellaonline.com/articles/art38073.asp>

research and analyse the experiences of men and to unpack the complexities of masculinity. Clearly the concept of oppression is dominant when discussing infertility, infertility treatment and treatment failure minimising the inequality of power between ‘the researcher’ and ‘the researched’ (Stanley & Wise 1983). It is therefore fitting that feminist perspectives underpin this qualitative piece of research in order to foster opportunities for social change in attitudes and practice whilst taking into consideration the impact of research procedures on the participants of the study. The purpose of this chapter is to define the elements that have informed this research and provide a comprehensive account of how this research was executed. This methodological chapter outlines concepts that provide relevance to the research and enhance the understanding of participants’ stories. The chapter shows how these concepts were used to both extract and analyse participants’ stories.

Feminist perspectives

Personal is political

A key feminist theme underpinning this research is that ‘the personal is the political’, meaning that ‘the system’ is experienced in everyday life (Stanley & Wise, 1983). The presence of ‘the system’ can be notably observed in the lives of couples who access ART. For example, couples access ART in the hope of becoming a traditional family. Couples are socialised from an early age to become parents so the social necessity of procreation becomes both personal as well as political. Furthermore, the act of procreation has traditionally been a private and personal issue. However, the introduction of ART has brought procreation out of the bedroom and into public and political forums. Judgements are made on the worthiness of couples or individuals to be parents, and also their right to ART (de

Lacey, 1998; Rickard, 2001). This interference in one's reproductive rights is not necessarily a new concept, if we consider the involuntary sterilisation of women with intellectual disabilities until the 1960's (Diekema, 2003). Recently, the Australian government unsuccessfully attempted to decrease the number of subsidised cycles that couples may access per year and attempted to minimise the number of cycles that women over 40 years of age were entitled to, reducing it to a maximum of three. Although serious lobbying by ART clinics and an infertility advocate group prevented these restrictions, the public debate brought to the surface many different opinions and ideals regarding the rights of consumers of these services to varying degrees of treatment.

Although attempting to control access to assisted reproductive treatments, the current government publicly promotes 'natural' procreation, encouraging couples not simply to reproduce but to reproduce an 'ideal' number of children. This is evident when the current treasurer Peter Costello commented during the budget season of 2004 that women would ideally have three children, 'one for Mum, one for Dad and one for the country'.

Self-disclosure

The term self-disclosure can be defined as the extent to which a person divulges information about herself/himself to another (Derlega & Chaikin, 1976), and in research encounters self-disclosure is advocated by several researchers as good feminist practice (Reinharz, 1992). I acknowledge that I bring to this study my own preconceived ideas and values. However, rather than attempting to suppress my subjective insights, I recognise and contemplate these throughout the entire research process. In this research I am positioned as an 'insider', sharing a similar history to participants. That is, I am also part of an infertile childless dyad who

has both sought and concluded treatment for infertility. The concept of being an ‘insider’ was given careful deliberation prior to the decision to undertake the research. Concerns addressed centred primarily on the possible consequences of self-disclosure to both potential and actual participants, as well as to the general public. The concept of self-disclosure to participants was non-threatening to me but not without concerns. Of perhaps the greatest concern was that by sharing my own experience, I would influence what information was divulged rather than the participant feeling free to reveal what they felt was important to them. Reinhartz (1992) illustrates this very point with an interviewee sharing that she was second-guessing what the interviewer wanted to hear based on what she had self-disclosed (p. 33). To counteract the likelihood of this happening, I chose to briefly disclose where I was situated prior to the recorded conversation but refrained from consistently sharing my stories unless the participant indicated that she/he was interested in knowing more. I also come from a background and era of nursing where personal involvement with patients/clients was discouraged. Especially frowned upon was a nurse who disclosed information of a private and personal nature, with labels such as ‘unethical’ and ‘unprofessional’ given to those who dared to share personal details with patients.

In addition to this, issues of personal comfort in disclosing information about my infertility arose. When conversing with participants, I am bound by confidentiality regarding participants’ stories. Furthermore, participants may choose which stories they are comfortable with being published and delete information that they do not wish to become public. I had no such privilege, nor were participants bound by confidentiality. However, the previously mentioned concerns were significantly outweighed by the benefits I perceived for self-disclosure.

Reinharz (1992) proposes that hearing other people's stories in the context of a conversation prevents the researcher from 'generalizing [sic] exclusively from her own experience' (p. 34). The positive effects of self-disclosure on many aspects of this research including recruitment, collection of stories and analysis are detailed later in this chapter. The decision to self-disclose publicly, however, was the focus of much angst. Public self-disclosure was in the form of a newspaper advertisement as well as an advertisement on the ACCESS⁸ website, posted for the purpose of recruiting research participants (see Appendix 1). The advertisement was placed in the front section of a newspaper which was local to both my workplace and residence (delivered free of charge to every household in the area), and the advertisement also appeared on an infertility website, thus exposing me as not only childless (not being of great concern as this is outwardly obvious) but disclosing also the reason for the absence of children (infertility). My self-disclosure in this case also meant the indirect disclosure of my husband, as colleagues and acquaintances were easily able to make the connection. This issue of 'dual' disclosure reinforces the point that the experience of remaining childless after infertility treatment impacts on both members of a couple.

Reciprocity

The statement 'disclosure begets disclosure' (Jourard, 1971, p. 27) illuminates the reciprocal nature of self-disclosure. Self-disclosure was considered integral to the feminist principle of reciprocity in this research. Reciprocity is defined as "the condition of being reciprocal", "mutual action" or "give and take" (Moore, 1997, p. 1126). Reciprocity in research essentially aims to minimise the inequality of

⁸ ACCESS is Australia's national infertility network which provides support, information and advocacy for those who are infertile.

power between ‘the researcher’ and ‘the researched’ (Kleiber & Light, 1978; Stanley & Wise, 1983). Apart from self-disclosing to participants, I invested time in rapport building with them, and throughout encounters willingly engaged in a mutual dialogue, thus creating a milieu of equality. Reciprocity also stemmed from the mutuality of interests in doing and participating in this research. Both the participants and I gained something from the encounters. For me, the benefits of the research were twofold. Apart from providing me with the opportunity to further my career, this research gave me the unique opportunity of reflecting on and exploring my own experiences in depth, which has been a therapeutic process. Participants articulated benefits for them as having the opportunity to tell their story to an attentive audience and be part of a study that has the potential to improve care for other infertile couples for whom ART is unsuccessful.

Oppression

There is a common perception that feminist research should remain research about women and be performed by women (Torkelson, 1996; Webb, 1993). Furthermore, it is accepted that women are oppressed and men are generally their oppressors (New, 2001). However, it has also been accepted that oppression is multi-dimensional (New, 2001), and Jackson (1997) reminds us that “feminism was born as a response to oppression” (p. 87) and further acknowledges that men also experience oppression. Men are dealt different hands under patriarchy. Dominant hegemonic masculinity insists that men prove their manliness by reproducing. Those who cannot conform by fathering a child are seen as failing to fulfill a crucial component of masculinity (Gannon et al., 2004). In an attempt to oppose the oppressive nature of hegemonic masculinities, and define new masculinities, Men’s Liberation was born (Connell, 1995). The new theories on

masculinities are inclined to follow feminist principles and advocate social justice for the purpose of creating a more equitable society (Connell, 1995). Stanley and Wise (1983) state that in order to resist oppression we need to know how and why it occurs, and with this knowledge we can prevent its occurrence.

As both the men and women who participated in this study do not conform to societal mores regarding reproduction, the use of feminist perspectives to underpin this research is linked with the oppression of women as well as men. For many years women have endured invasive ART treatments and the gendered nature of service provision has ensured that the dominant medical discourses are privileged (Raymond, 1993; Rowland, 1992). However, Carmeli and Birenbaum-Carmeli (1994) suggest that the focus on women alone has resulted in the oppression of men, with subsequent limited male treatments for infertility. The inequality experienced by both men and women has the capacity to adversely affect both partners of the couple. Furthermore, the inability to fulfill the criteria for hegemonic masculinity makes participant men vulnerable to oppressive behaviour by other men (Connell, 1995). Using feminist thinking and approaches, the oppression of these couples can be minimised throughout the research process by taking into account the stories of both members of the couple and affording them a voice.

Stories

Although the term story has multiple meanings and contexts, it is commonly defined as: “a narration of a chain of events told or written in prose or verse” (Butterfield, 2003, p. 1593). The art of *storytelling* is one of the most enduring modes of conversation and remains one of the earliest skills learned and

encouraged in our society. Kemper (1984) proposes that storytelling is the foundation of language that develops gradually throughout childhood, the content of which stems from our experiences. Life stories are particularly valuable when told for research purposes as they “reveal how life events affect people and how people give meaning to these events” (Minichiello, Sullivan, Greenwood, & Axford, 1999, p.134). The life stories gathered for the purpose of this research hold particular value as this grants participants the opportunity to be heard about the effects of ART in their lives.

The telling of stories can make sense of life events and provide understanding and bring meaning and order to an otherwise chaotic situation (Polkinghorne, 1988). This point of view is supported by Pennebaker and Seagal (1999), who assert that “painful events that are not structured into a narrative format may contribute to the continued experience of negative thoughts and feelings” (p. 1243). Through an approach that uses conversation as a way of gathering stories, this research intends to assist in providing nurses and other health care professionals with an awareness and some understanding of the impact of negative outcomes of ART, as many who access treatment do not become biological parents.

Frank (1995) explains:

Storytelling is *for* an other just as much as it is for oneself. In the reciprocity that is storytelling, the teller offers herself as a guide to the other's self-formation. The other's receipt of that guidance not only recognizes but *values* the teller. The moral genius of storytelling is that each, teller and listener, enters the space of the story *for* the other. Telling stories in postmodern times, and perhaps in all times, attempts to change one's own life by affecting the lives of others. (p. 17-18)

Frank (1997) also elaborates on the importance of those who are ill telling their stories in their own voice, particularly as medical categories operate by presenting

the individual as not simply *having* but *being* the illness/disease. Although the participants in the current research were not in poor health, they had been interpellated (called upon) by the medical profession and were therefore perceived to *be* an infertile person rather than *have* a diagnosis of infertility. A lack of individualisation becomes further apparent in the way in which people with a ‘condition’ or illness are categorised. Although there are numerous circumstances that may contribute to a person’s diagnosis of infertility, they continue to be positioned as *infertile* without acknowledgement of the unique situation for each individual. This generalisation and interpellation of infertile childless people changes the identity of the person or persons categorised, if not personally then certainly socially. Therefore, being encouraged to tell their stories in their own way may assist participants in retrieving their preferred identity independent of what is referred to in Frank (1997) as their *hailed* identity (i.e., the identity that is placed on them by an institution) (p. 32-33).

Apart from being a process with the potential for empowerment, storytelling is a powerful educational tool that has the ability to assist and inform the care delivered by nurses and other health care professionals. As Lumby points out: “Often the oral story is the real story – one which discloses essential meanings for the provision of effective and sensitive care” (1992, p. 14).

An awareness of the impact that both the actual condition and the inherited identity brings provides a greater insight into what it is like for individuals and couples deemed ‘infertile’ and ‘childless’. Such stories contribute to the knowledge base of nursing and have the potential to enhance holistic care. The goal for presenting stories was to use, as much as possible, the participants’ own

words and to preserve the context in which they were said so that the reader may gain an authentic representation of their experience.

Eliciting participants' stories was considered vital to gain insight into the meaning participants attach to certain life event or events *they* considered particularly significant. Frank (1997) stresses that stories are re-shaped as they are re-told, and become the [healthcare] professional's story of the ill person's story (p. 37) and therefore become part of their professional discourse. As it is not possible to present the entire story of all participants, my narration serves to guide the reader through their stories illuminating the most dominant elements thus re-shaping their stories. For this reason, large sections of participants' stories are used verbatim to weave a common thread throughout the shared narrative. As well as contributing to the rigour of the study, presenting the large sections of participants' stories verbatim was considered a more powerful account of experiences. Although I am producing an academic text, an oral account brings to life a greater display of emotions and feelings in the words of those who have experienced them.

The positive outcome of storytelling is that it enhances nurses' and other health professionals' understanding of situations, and individuals within those situations, thus enhancing the likelihood of holistic care (Banks-Wallace, 1999; Benner et al., 1997; Bowles, 1995; Cronin, 2001; Pennebaker & Seagal, 1999). Within individual stories, insights may be gained about the cultural, social and economic background of participants, thus increasing understanding about individuals in particular contexts. This contribution to nursing knowledge has the potential to influence the care that is available to people (Banks-Wallace, 1999). Intricacies within stories may alert the reader to a variety of issues experienced by the

storyteller, and may allude to the order of their preferred prioritisation. Presenting stories as told by the participants gives the reader access to data that has not been manipulated, reduced and changed to fit within a strict methodological framework.

In addition to assisting nurses and other health care professionals to better understand what it is like for couples and individuals to remain involuntarily childless, the storytelling approach may prove to be a therapeutic process for participants. I agree with Hutchinson, Wilson, and Skodol Wilson (1994) that catharsis often occurs through having the undivided attention of a genuinely interested party, and being able to convey innermost thoughts and feelings in a safe, non-judgemental and confidential environment. Also I suggest, along with Frank (2002), that “being narratable implies value and attributes reality” (p. 5).

Apart from the potential impact that this research will have on the delivery of care for those who access ART and remain involuntarily childless, additional positive outcomes for participants may include a sense of being valued as worthwhile and narratable beings.

Narrative

According to Polkinghorne (1988) the term narrative has many and varied definitions and subsequent meanings. Commonly accepted definitions may be found in the Collins Australian Dictionary and include:

NOUN 1. an account, report, or story, as of events, experiences, etc. 2. (sometimes preceded by *the*) the part of a literary work that relates events. 3. the process or technique of narrating. ADJECTIVE 4. telling a story: *a narrative poem*. 5. of or relating to narration: *narrative art*. (Butterfield 2003, p. 1083)

These definitions equate narrative and story as one and the same. However, for the purpose of this research, narrative and story are distinguished by key elements to facilitate the use of both terms as having separate and individual meanings.

Wiltshire (1995) differentiates between narratives and stories with the distinction that narratives are more structured and formal accounts that contain additions and omissions from the original accounts. Therefore, the term narrative will not be used when speaking exclusively about participants' accounts of their life events but in my interpretation and guidance of their stories. Within the analytical process, a narrative is presented that will contain a more structured and formalised account of participants' stories. These formalised accounts will contain both input from myself as well as excerpts from the stories and conversations with other participants that enhance and highlight the dominant issues of the initial story. The narrative, which becomes the thesis, also weaves the stories, and it is my narrated account with literature to support the stories that forms the central plank of this thesis.

Inclusion criteria

Inclusion criteria for participants were determined as being couples in heterosexual marital relationships who: have accessed treatment for their infertility and have now ceased treatment, have no children, (biological, adoptive, surrogate or from a previous relationship), have made a decision to remain permanently childless, are fluent in English, and are willing to talk about their experiences. Although same sex couples, those in de facto relationships, divorced men and women and single individuals may have similar issues regarding infertility and childlessness, couples in heterosexual marital relationships were

targeted for the purpose of this research due to the greater societal expectation on this group to procreate.

As the research was interested in collecting the stories of couples who remained involuntarily childless after ART, the aim of recruitment was to attract an even number of both men and women into the study. The criterion for participation in the study regarding the ability to speak and understand English was established to ensure that no aspect of the participants' experience would be lost through the interpretation of a third party. All information and forms were presented in English.

Recruitment

The decision not to recruit participants using medical records was due to my reluctance to be limited to set service providers and my intention that this research be seen as independent from ART services. Recruitment of participants was by an advertisement in a local newspaper and on a national infertility network website. In writing the advertisement, I had considerable difficulty with choosing language that would not be considered negative. I believed that negative language would not only discourage couples from responding to the advertisement but contribute to the stigmatisation and marginalisation that those eligible for participation may have already been experiencing. However, negativity seems to be the grounding of existing language for couples who have been unable to have children. Instead of using the word 'childless', I finally settled on phrasing a question that downplayed the negative connotations by asking 'Have you been unable to have children?'

An advertisement was placed in a local paper as well as on an infertility support group website (see Appendix 1), and members of the public who had ceased ART and remained involuntarily and permanently childless were invited to participate in the study. Potential participants were invited to contact me either by telephone or email for further information regarding the study. During this initial contact, potential participants were asked if their partners would also be willing to participate in the study. Interested couples who fulfilled inclusion criteria were provided with an introductory letter (see Appendix 2), participant information sheets (see Appendix 3), a list of possible questions that may be asked during the conversation (see Appendix 4), and the contact details of a specialised counsellor and support group for childless couples (see Appendix 5). Participants were invited to contact me after reading this information if they remained interested in participating in the study. At this point, appointments for meetings were made.

Within the advertisement, I chose to identify my experiences in the research area, in the belief that a common bond or experience may serve to enhance both recruitment and conversation. Sharing a similar background to participants can be an advantage as it ensures a greater understanding of the phenomenon (Minichiello, Madison, Hays, Courtney, & St John, 1999). Infertile childless women are often misunderstood by those who have not had similar experiences (Peters, 2003). My self-disclosure allowed for ease in recruitment and enhanced aspects of the encounter, contributing to the depth, richness and quality of the stories gathered.

As I envisaged that men would not be likely to answer advertisements regarding participation in a research study of this nature, the recruitment of women served

to also recruit their male partners. It is the experience of other researchers⁹ that men will generally not initiate contact via answering advertisements in the newspaper, so when women answered the advertisement they were asked to invite their respective male partners to participate in the study. Thus men were generally recruited through the involvement of their partners.

Despite actively recruiting for a period of twelve months, very few people came forward who were willing to participate in the study. Of those who expressed an interest in participating, only six couples met the criteria. A further three women who were either separated or divorced from their husbands expressed their wish to participate in the study but were declined as the current research focus is on couples' experiences. Two couples who expressed interest in participating but had not yet decided whether to cease ART treatment were also not included in the study. There were eight responses from people seeking support for difficulties they were encountering due to failed ART but none of these were interested in participating in the current study. These people were given the names and numbers of the infertility support networks and counsellors shown in Appendix 5.

Twelve people (6 couples) were initially recruited to the study and encounters were held on a one-to-one basis. Two people (one couple) later withdrew from the study without explanation. I met with participants for the purpose of collecting stories on one occasion only but participants were given an opportunity to further clarify or add to their stories at a later date if they wished. The sample size allowed for the detailed analysis of the narrative. Polit, Beck and Hungler (2001) affirm that "sample size should be determined on the basis of informational

⁹ R. Cook, personal communication, November 29, 2002

needs" (p. 248). The exceptional quality of the stories collected throughout conversations with participants ensured that extensive amounts of relevant information were available for presentation and analysis.

Conversation/Interactive discourse

Conversation is a dialogical interaction between two or more people. The art of conversation is not purely one person talking to another, but requires interaction by all participants. Essential elements of dialogical interaction include both listening and the ability to see another's perspective (Sakalys, 2000). Interaction of this nature ultimately constructs a narrative that has been co-created by all participants of the conversation (Sakalys, 2000). My role in this interaction can then be viewed as a co-creator of the text. That is, I facilitated the storytelling process by triggering conversation and encouraging the articulation of participants' memories of events. In the current research my input as well as that of the participant was required in order to enhance discussion and promote the telling of stories.

Conversational interviews are typically unstructured or semi-structured in nature and promote flexibility in the collection of narratives from research participants, thus allowing further exploration of issues that may not necessarily have been identified prior to the commencement of the interview (Polit et al., 2001). The unstructured characteristics of conversational interviews provide a setting that enhances equity in the focus of the conversation. This promotes a liberating effect for the participant, who chooses what they wish to discuss. Whilst using the basic concepts of conversational interviews to guide the collection of stories from participants, I chose to remove the word 'interview' from the process, preferring

instead the more informal terms of ‘conversation’ and ‘encounter’ to promote a greater sense of equity and autonomy for the participant within the story collection process. The concept of conversing with participants rather than conducting an interview appealed to me for a number of reasons. The flexibility promoted by this method of gathering narrative allows the research participant to tell their story in a comfortable forum. As conversation is very much a part of everyday life, I believed that research participants would be more likely to be relaxed, and this approach would promote the flow of speech and capacity for fluent storytelling.

Conversing with participants

Oral interviews provide an invaluable means of generating new insights (Anderson & Jack, 1991). However, Jackson (1997) points out that there is an inequality in the research process, as throughout the conversation it is expected that the participant will impart certain information deemed valuable to the research project, thus placing pressure on the participant to disclose. In an attempt to minimise pressure on participants, it was explained to them that the purpose of the research was to tell *their* story of being childless after infertility treatment, thereby allowing them to choose what they wished to divulge in and through their stories.

The importance of eliminating agendas (as much as possible) from the conversational interview is illuminated by Anderson and Jack (1991), who suggest that if preconceptions of what the researcher expects to hear, or seeks to have included in oral accounts, overrides what the participant wants to convey, opportunities to explore essential aspects of the storyteller’s experience may be lost. In an attempt to prevent essential stories from being stifled and minimised,

participants were initially asked to simply ‘tell their story/stories about infertility treatment, events leading up to treatment cessation and remaining childless’. This gave participants the freedom to discuss whatever aspects of their individual experiences they considered important, as well as decreasing the likelihood of the researcher guiding the encounter to fit in with pre-conceptions of what was considered important and essential information to be included.

Men have been given fewer opportunities to tell their story regarding remaining childless after infertility treatment, either through being ignored, by being thought of as having the same story to tell as their female partners, or alternatively by being presumed to have opposite or conflicting emotions and agendas regarding the whole concept of parenthood. This research not only aimed to provide men with a forum that enhanced conversation, but allowed men to share what they felt was important to them regarding their experiences and the way in which they were positioned in the phenomenon of childlessness after infertility treatment.

In this study I was guided by the belief that people are better able to express themselves effectively using verbal language rather than by using a written format such as questionnaires (Croyle & Waltz, 2002). This further supports using conversations for the collection of participants’ stories for this study. Findings of the study by Croyle and Waltz (2002) indicate that in general life situations men and women are equally aware of their emotions. However, emotional awareness related to intimacy or conflict within relationships was significantly greater in women than in men. As infertility and involuntary childlessness involve issues of both intimacy and conflict, men may not be as emotionally aware of problems in their relationship.

Certain studies investigating emotional awareness and expressiveness attribute differences between men and women in emotional awareness and expression to learned behaviour (Kelly & Hutson-Comeaux, 1999; Moore & Haverkamp, 1989). Riessman (1993) acknowledges that men and women have different yet “distinctive vocabularies of emotion” (p. 43). If this is the case, men’s emotions, and more specifically their awareness of these emotions, may indeed be similar to those of women but repressed due to societal gender stereotyping. However, throughout conversations with participants, it became evident that both the men and women involved in this study were equally equipped to disclose their stories related to their infertility and childlessness.

Historically, women are recognised as being more willing to self-disclose than men (Jourard, 1964). If this is so, women may prove easier to converse with than men, as they are accustomed to articulating their stories. However, previous research by Peters (2003) has shown that women may be reluctant to disclose issues related to their infertility due to the possibility of being stigmatised. Throughout the process of collecting participants’ stories for the current study, little difference between men and women regarding both willingness and ability to articulate their stories was noted. To facilitate conversations with participants in this study, particular attention was given to rapport building, as it has been well documented that the level of disclosure increases in the presence of a positive relationship (Certner, 1973; Dindia & Allen, 1992; Mikulincer & Nachshon, 1991).

Women may provide two different accounts of their lives. One perspective is heavily influenced by, traditionally, a dominant male stance, and constitutes a publicly acceptable position to uphold. The other belongs to their personal

experience; that is, it is commonly the less socially talked about or less acceptable but nevertheless “immediate realities of a woman’s personal experience” (Anderson & Jack, 1991, p. 11). Where these experiences vary from dominant positions, women’s perspectives may be stifled. In order, then, to ensure accurate interpretation and understanding of what women say, we must be aware of and regulate our listening to capture both of these accounts (Anderson & Jack, 1991). It may be that men also provide joint perspectives when recounting their experiences. In the case of experiences relating to infertility, men may present a version of events that is commonly accepted; that is, men are less emotionally involved and therefore less stressed than women if ART fails. Alternatively, they may relate the dominant perspective of their partner (dominant, as historically infertility and childlessness have been seen as primarily women’s issues), with the dominant issues relating to their partner’s experience and not necessarily their own. Therefore, listening to the stories told by all participants, regardless of their sex, and being vigilant and receptive to all possible perspectives that the participants conveyed was imperative in order to gain access to the individual realities of both members of the dyad.

Apart from gender differences between parties to this conversation, a variety of other differences may warrant exploration or consideration regarding the type and quality of the stories collected. An interviewer’s age, ethnicity, culture, and previous life experience all impact on the process of conversation (Hutchinson, Marsiglio, & Cohan, 2002). Further, researcher self-disclosure assists in building rapport with participants and therefore results in a richer narrative being gathered (Reinharz, 1992; Wilde, 1992). In this case self-disclosure of my similar experiences to the participants of this study may have created a milieu of

acceptance, so those sharing their stories may have felt more at ease about disclosing sensitive information.

Venues for conversations

A safe environment for both participant and myself was imperative for the collection of stories relevant to the research question. Effective conversation results from both parties being relaxed and comfortable and therefore requires consideration of such things as temperature of the room, lighting, furniture and general ambience.

Apart from a physically safe and comfortable environment, conversation may be enhanced by the provision of a psychologically safe environment. This is one in which the participant is protected from others who may eavesdrop or accidentally overhear part of or the entire interview. People may feel more comfortable talking in their own homes, but conversing with couples at their residence brought with it further considerations of privacy and disclosure.

Whilst audio-taping a conversation with one partner of a couple in their own home, consideration of proximity of the partner not involved in the conversation at that time was taken into account. If participants were not comfortable disclosing information due to the perception that their partner may have been listening, the purpose of the encounter would have been jeopardised.

Participants were given a choice of venue for the purpose of collecting stories. Although other venues were made available to all participants for the purpose of the conversations, all chose to use their own homes. I offered to arrange another date and time for conversations if participants felt that the time delay waiting for

their partners to complete their meeting was excessive. However, all participants preferred to complete the meetings in one day due to other commitments.

Ensuring that both partners were going to be in the general vicinity at the time of the meeting served to enhance my safety. I carried a mobile phone and informed the participants on arrival at their home that I had an appointment elsewhere immediately after the current meeting.

Conversational triggers

Polkinghorne (1988) proposes that if a research participant wants to share an account of their experience, the type of question asked becomes insignificant, and questions phrased to elicit short answers will often result in lengthy responses. In this study, in order to encourage participants to convey their stories and not inhibit the conversation process, the conversation was generically initiated by asking the participant “Tell me your story of remaining childless after infertility treatment”. If participants required more guidance to find a starting point to their stories, they were asked to tell me about their experiences of infertility, ART and being childless.

I considered it imperative that I felt or at least gave the appearance of being comfortable with the range of responses that conversational triggers elicited. Conversation related to highly sensitive issues such as sexuality, sexual intercourse, and masturbation, which are all topics very closely associated with assisted reproductive medicine, were all discussed freely to encourage participant narrative about an integral aspect of the phenomenon studied. If I were not comfortable with these issues, I considered it unlikely that participants would

freely discuss these topics, thus possibly resulting in the omission of crucial points of an individual's story.

Meeting the storytellers

The stories of five married couples (five men and five women) who participated in this study were explored. A brief synopsis of each couple's experiences will be presented to assist the readers' understanding of the position of the participants within the context of their stories. Individual participants have been given pseudonyms to prevent their identification. Pseudonyms were often chosen by participants themselves and reflect no resemblance to the participant other than corresponding to sex.

Throughout the synopsis of each couple, estimates of times and ART cycles are often given. Accuracy regarding dates and the number of completed ART cycles was difficult for participants to recall. The very demanding nature of ART cycles, and the time frame in which cycles were undertaken, often tended to blur participants' recollection of the exact number of ART cycles they completed.

Greg and Andrea

Greg and Andrea had ceased ART six years prior to our conversation. Their infertility was due to both male and female factor. Their quest for reproduction began many years earlier, initially with an unexpected pregnancy that resulted in a traumatic miscarriage. They describe persevering with an infertility work-up¹⁰ for some years prior to accessing ART. They had four stimulated cycles of IVF over approximately five years with no pregnancies resulting. The catalyst for their

¹⁰ An infertility work up is a series of tests and procedures that may assist in the diagnosis and treatment of fertility problems

decision to cease treatment was a stimulated IVF cycle where Andrea had fourteen oocytes collected and not one of them fertilised. Prior to this cycle, Andrea had experienced many difficulties throughout treatment, including an infection introduced during embryo transfer and inconsistent care. Both Greg and Andrea began to have grave concerns for Andrea's health and both describe themselves as depressed at the cessation of treatment, which they attributed to the result of both the treatment itself and treatment failure.

Alex and Sarah

Alex and Sarah accessed ART for twelve and a half years, undergoing multiple and varying treatments. They ceased treatment approximately 10 years prior to our conversation. The cause of their infertility was female factor, due to a long and complicated medical and surgical history. Sarah became pregnant after one ART cycle, which unfortunately resulted in a miscarriage. Alex and Sarah discontinued ART after their treating doctor refused to continue treating Sarah due to extreme risks to her health. After the cessation of ART, Sarah describes experiencing a four-year period of emotional and psychological hardship that impacted heavily on all facets of the couple's life, and in particular, their relationship.

James and Rosemary

James and Rosemary were diagnosed as having idiopathic infertility, meaning that the cause is unknown. Prior to accessing ART they had five years of infertility work-up. James and Rosemary proceeded to go through eight IVF cycles over a twelve-year period with one resultant pregnancy. They experienced an IVF miscarriage when Rosemary was 14 weeks pregnant. This experience changed

this couple's perception and attitude to treatment. James initiated the cessation of ART, a decision that was not initially well accepted by Rosemary until some years later. Rosemary describes a sense of peace with the decision later when being empowered to make the decision not to further pursue an offer of alternative treatment. Both James and Rosemary have professional occupations and Rosemary remains actively involved in support networks for those who are infertile.

Carl and Aimee

Carl and Aimee had attempted to have a child for approximately eight years. Their experience with ART included three stimulated cycles and a number of frozen embryo transfer cycles without a positive pregnancy result. The couple were initially diagnosed with male factor infertility, but during the course of ART, Aimee was diagnosed with endometriosis. Carl and Aimee decided to cease treatment less than six months prior to our conversation after enduring a particularly gruelling cycle where they perceived ART staff as unprofessional and unsupportive. Ceasing treatment was motivated by the negative impact that ART had on the physical, emotional and financial aspects of their life. They were in the process of changing their focus in life to one that no longer included children.

Derek and Anna

Derek and Anna attempted to conceive for approximately one year prior to seeking medical advice, and accessed ART for approximately ten years after being diagnosed with female factor infertility. Treatment resulted in two pregnancies for this couple, one resulting in a miscarriage when Anna was 12 weeks pregnant, and the other a termination of pregnancy at 21 weeks due to

severe genetic abnormalities. The couple ceased treatment after this termination, which had occurred approximately four years prior to our conversation. They are striving to move on with their life as a couple without children by changing their lifestyle and focus in life.

The couples participated in this research to create an awareness of what it is like for people to access ART and remain childless. They acknowledge the lack of information available, resulting in a lack of societal awareness and understanding, regarding remaining involuntarily and permanently childless. Among their greatest concerns was their wish to highlight the reality and hardships of infertility and related treatments as well as the impact – both negative and positive – that remaining childless can have on all facets of a couple's life. The storytellers wished to share their stories so that others in similar situations may find the transition to a childless existence easier in the knowledge that they are not alone.

Rigour

Hall and Stevens (1991) suggest that rigour can be achieved by ensuring adequacy of the inquiry. Hall and Stevens (1991) elaborate by stating that adequacy and therefore rigour may be achieved by following several criteria including; reflexivity, credibility, and rapport. These criteria, as well as the criterion of auditability proposed by Guba and Lincoln (1981) and Sandelowski (1986a), are addressed in relation to how rigour was attained for this study.

Reflexivity

Gergen (1999) affirms that self-reflexivity means, 'questioning ones own position' and argues that in doing this we can be receptive to other standpoints (p. 162). Throughout this research project I used a reflexive approach and kept a

journal, a tool advocated by Lincoln and Guba (1985) to ensure rigour in research.

In my reflexive journal I documented interactions and reactions to various situations that occurred throughout the process of collecting and analysing stories, thus enhancing my self-awareness.

Reflexivity is not merely reflecting on the dynamic of the encounters and writing an entry in a journal, although this may enhance the reflexive process, but requires that the researcher be mindful of the positions held by participants, and their own positions in relation to the participants and the research (Martin-McDonald, 1999). Horsburgh (2003) asserts that ‘reflexivity may be demonstrated by use of the ‘first person’ when the researcher describes the aspects of the research in which (s)he has had personal involvement’ (p. 308). Throughout this chapter, I have written in the ‘first person’, thus providing the reader with information that indicates how I have personally impacted on the study. Furthermore, from the beginning of this thesis I position myself in relation to the current study, and acknowledge that the findings of this research are but one interpretation of participants’ accounts and this interpretation is influenced by both my historical and present realities.

Credibility

Guba and Lincoln (1981) suggest ‘credibility’ as a criterion of rigour, and define a credible study as one that presents descriptions or interpretations of an experience in such a way that those having that experience would immediately recognise it as their own. Although Lincoln and Guba (1985) advocate member checks as an essential step in establishing rigour in qualitative studies, I decided to employ different measures to enhance the credibility of the current study for the following reasons. According to Sandelowski (1993), the trustworthiness of a study may be

threatened by asking participants for clarification of the data as participants often have different goals to the researcher and may look for concrete descriptions rather than abstract ones. Furthermore, Throsby (2004) considered that her decision to ask participants to review their transcripts produced “an unwelcome burden of work for the participants” (p. 50).

Another problem with participant clarification lies within the time that elapses from the data collection to the actual moment when the participant checks for correct interpretations. Sandelowski (1993) highlights that experiences may have been forgotten or distorted over time, resulting in the participant wishing to change, add or remove certain elements of their story from the study. All of these possibilities would threaten the trustworthiness of the study (Sandelowski, 1993). Sandelowski (1993) proposes that “rigor is less about adherence to the letter of rules and procedures than it is about fidelity to the spirit of qualitative work” (p. 2). Frank (1995) argues that storytellers tell their story better than anyone. Therefore, I considered meticulous handling and presentation of the data imperative to ensure the rigour of this research. I listened to the recorded conversation whilst reading and checking the transcripts and thus ensured the accuracy of the translation of the spoken word and the context in which it was said. By doing this, participants would be able to identify the stories presented as their own.

Rapport

Self-disclosure increases rapport, particularly in cases where the ‘researcher’ and the ‘researched’ share experiences pertaining to the focus of the research, and thus the encounter is more reciprocal (Ellis, Kiesinger, & Tillmann-Healey, 1997; Reinharz, 1992). During our encounters I found the participants and I were

relaxed and conversed effortlessly. Our common experiences related to infertility and ART meant that jargon did not need to be explained, and there was therefore no need to interrupt the flow of dialogue. Hall and Stevens (1991) state that rapport can be appraised by the quality of the information shared, participant comfort, and their inclination to recruit other participants. In the case of this research, good rapport between participants and myself is evident in the richness of participants' oral accounts and their efforts to recruit other couples to the study.

Auditability

Sandelowski (1986a) and Guba and Lincoln (1981) affirm that when another researcher can clearly follow the 'decision trail' used by the investigator from the beginning of a study until the end, a study and its findings are auditable. From the beginning of this study, I have positioned myself in relation to the research to inform the reader of how I may have influenced the content of the research. As well as this, large sections of participants' spoken words are presented in both the findings and analysis to show how I arrived at particular interpretations, thus contributing to the rigour of this study.

Ethical concerns

Confidentiality

Confidentiality between the different couples was maintained but confidentiality between partners was not be able to be maintained if both partners participated in the study, as both knew of the other's involvement. Also it is reasonable to expect that they will be able to identify their own partners by their stories. Tolich (2002) refers to ethical concerns regarding both internal and external validity when conversing with connected persons such as marital partners. Tolich (2002) suggests that consideration be given to joint interviews for the purpose of research

in order to eliminate the risk of a breach of internal confidentiality. As Tolich (2002) acknowledges, data collected in joint interviews is rarely as lucrative as data collected in individual interviews. As the objectives of the current research included gaining individual accounts of both members of a couple, conducting joint interviews was not considered a viable or acceptable solution. However, I recognised that the problem of internal confidentiality did need to be addressed to protect participants from potential harm. Therefore, prior to the conversations, it was explained to participants that whilst I would at all times act to protect confidentiality and anonymity there was a very real chance that their partner would be able to identify their stories, and therefore confidentiality within couples or internal confidentiality may not be able to be maintained. This gave the participant an opportunity to withdraw from the study or only divulge what they were comfortable to have disclosed to their partner. As well as this, participants were offered a copy of their audio taped encounter in audio form, or if preferred were given a hard copy after transcription. The purpose of this was to give the opportunity for participants to review their text and confirm that they were comfortable for me to use any or all information for publication.

All participants involved in this study were assured of anonymity through the use of pseudonyms and distortion of other identifying features, if any were used in text. It is assumed that if the researcher is able to guarantee that information relating to personal details specific to participants will be either concealed or altered, then individuals will be more inclined to participate in the research (Minichiello, Aroni, Timewell, & Alexander, 1995). The participants' actual names only appear on the consent forms to further protect privacy. These documents, along with the audio tapes of encounters, are stored in a locked area in

accordance with the National Health and Medical Research Council (NHMRC) (1997) guidelines and will remain so for no fewer than five years following publication of the thesis. The computer disks used for the purpose of transcribing encounters are also stored with the audio tapes. All hard copies of the transcribed encounters were destroyed on completion of the project.

Transcription

A professional transcriber transcribed the audio-taped conversations. This person was subjected to the same requirements to respect and to maintain confidentiality and anonymity as stated in the letter of introduction. As language is acknowledged as being very much contextual (Gadamer, 1989), the correct interpretation of a phenomenon relies heavily on what is said remaining in context. Therefore, after the tapes of the encounters were transcribed, I listened to the recordings in their entirety and checked the transcriptions for discrepancies as recommended by Wellard and McKenna (2001). Apart from inconsistencies being amended in the transcripts used in the current research, emphases on words and other significant events that occurred throughout the conversation (e.g., meaningful silences, displays of emotion, and tone of voice) were noted on the transcript to promote understanding of the story in the context in which it was told.

Consent

Consent for this study was obtained in a variety of ways. Participant information sheets were mailed out to participants prior to the encounter to ensure they had the opportunity to read and understand the purpose of the study, what was required of them, potential risks, benefits and costs to them and their rights as a participant.

Prior to the commencement of the conversation, I asked the participant for clarification of understanding of the information supplied. Participants were then required to sign a form giving informed consent (see Appendix 6). Prior to signing consent forms, participants were made aware that if during the course of the encounter they wished to withdraw their consent, they were able to withdraw either partially or totally from the study without fear of retribution.

Participant autonomy and privacy

This study was given ethics approval by the relevant institutional ethics committee (IEC). As highlighted by Streubert and Carpenter (1995) there is no forewarning about what may transpire in conversations. Those who chose to participate in the study were therefore informed that they could choose to cease the conversation, retract statements and/or withdraw from the study at any time. Participants had maximum control over what information was used in the study, thus minimising any risks associated with the publication of stories collected. One couple withdrew from the study after the interview through a letter to the university's ethics committee.

Participants had prior knowledge of the types of questions asked as these were mailed with the participant information sheets. I discussed any concerns the participants may have had prior to commencement of the conversation. The research objectives were made clear to participants and they were given the opportunity to discuss any concerns they may have had regarding discussion topics.

As the research involved conversing with both parties of a couple, it was anticipated that some participants may ask questions regarding what their partner

divulged during their conversation. Prior to commencement of all conversations, I emphasised that no information would be disclosed by me regarding participants' stories and that participant privacy would be maintained at all times.

Emotional considerations

I acknowledged the potential for emotional distress associated with participation in this project. As participants had the opportunity to discuss issues that are not widely accepted for discussion in general society and have an attached stigma, it was anticipated that participants may find this opportunity a helpful and cathartic experience (de Lacey, 2000). However, due to the sensitive nature of the phenomena being studied, there was a possibility that some or all of the participants may have become emotionally distressed during the encounter. Although being particularly careful not to take on the role of a counsellor, I provided adequate support and information to participants to ensure their emotional well-being and minimise any distress arising from the encounter.

Participants were given details of professional counsellors who specialise in infertility counselling, and who had previously agreed to consult with any of the participants of this study should they require professional counselling. In addition, details of a support group were provided to participants. The intention of supplying this information was not to decide when participants required counselling, but to inform them of resources available should they choose to access them. Counsellor details and support group information was mailed to potential participants prior to the encounter with information sheets and the letter of introduction.

Unfortunately, professional counselling was unable to be provided free of charge. However, within the support group identified, contact people were available to talk to participants at no financial cost. Counsellors with this speciality are limited and none provide a free service. A list of counsellors with relevant backgrounds and qualifications was given to participants to allow them to choose what service they accessed if they felt they require counselling. Providing a list of several available counsellors denoted my impartiality to any one particular counselling service.

The counselling services mentioned were not recommended services but purely a notification of services available. It was envisaged that if individuals became distressed during the course of the conversation, it was due to a pre-existing cause that may have been triggered by the recall of lived events and not as a result of the conversation itself. This conversation may have provided the participant with an outlet for issues that would require addressing at some stage of their life.

Researcher burden

Although Cowles (1988) recommends staggering encounters to minimise researcher stress, most encounters with individual couples were held consecutively as this was more convenient for the couple. This meant I was listening to couples' stories for approximately four hours with only a short break between. As I found their stories interesting, concentration was not a problem; however, intense listening for this period of time proved to be tiring and stressful at times. Throughout encounters with participants and working closely with their stories, there were times when varying emotions surfaced that stemmed from my own experiences of infertility and childlessness. Cowles (1988) affirms that encounters can be physically, emotionally and psychologically exhausting,

especially if the participant experiences emotional distress. Reinhartz (1992) suggests that the reason researchers become distressed is that they learn that there is more pain in the participants' lives than they previously realised. Like Sullivan (1998) I found that at various stages of the research, I was affected by these couples' stories. Initially listening, and later reading and analysing participants' stories often provoked in me feelings of sadness and at times anger at what these couples had endured.

Beale, Cole, Hillege, McMaster and Nagy (2004) discuss the detrimental impact that qualitative research interviews may have on the researcher, and recommend the formal debriefing of those who are involved in interviews on sensitive topics. Although I did not undergo formal debriefing, unlike Sullivan (1998) who chose to deal with her feelings alone, when I found stories particularly distressing, I discussed them with my supervisors which assisted in helping me to process these feelings. At these times I also found writing in my journal to be a therapeutic exercise and at other times I felt the need to step back from my research until I felt better able to cope with the feelings that it uncovered.

Analysis

To assist with the identification of dominant stories throughout the individual transcripts, I initially considered, but later rejected, using computer programs. The primary reason for this was that the entire process of the current research revolved around the individual and humanistic elements of stories being told, collected and then presented in the manner and context in which the teller intended. Introducing technology in order to decipher what participants actually meant was in direct contradiction to the objectives of the current research. In addition to the fact that

learning to use the software effectively is a time consuming process (Barrett, 1998), computer programs lack the ability to attach meaning to text (Sandelowski, 1995), and therefore themes identified by the program may not necessarily be compatible with the context in which the oral story was spoken. After careful deliberation, I decided that to enhance understanding of participants' stories, the submersion of oneself in the text (as recommended by Anderson & Jack, 1991) was necessary to allow individual voices and concerns to become obvious to me.

The structure of stories consists of a beginning, middle and an end (Polkinghorne, 1988). As well as this, stories consist of a protagonist or character within a setting, a predicament or problem, and a resolution to that problem (Mandler, 1984; Stein & Policastro, 1984). Using these ideas as guides, multiple stories were identified within all participants' transcripts. Dominant stories within individual transcripts were identified by the emphasis participants placed on them either by repetition or expression. This process involved reading the transcripts from conversations multiple times whilst listening to the audio-taped conversations, in order to obtain a comprehensive understanding of the content. Subsequent to dominant stories being identified within individual transcripts, those that were common, both within the dyads and between individuals, were identified. After the completion of this stage of identification, stories that best represented all participants' accounts were presented in the thesis.

It is an unfortunate fact that the stories gathered from the dialogical encounters between participants and myself will never be presented in their entirety. Prior to gathering the first of these stories it was my intention to do just that. However, as Riessman attests "It is naïve to think one can 'just present the story' without some systematic method of reduction" (1993, p. 43). How, then, is it possible to reduce

participants' stories without omitting text that may be vital to understanding the phenomenon in question? To what extent the information included in the final draft of the story does the text justice was also of concern to me. The decision not to deconstruct the stories in order to analyse meaning (as described by Riessman, 1993) may be explained by my reluctance to risk changing the context, and therefore the meaning, of the text as a whole.

For the purpose of analysing participants' conversations, this research draws heavily on work by Anderson and Jack (1991) who inform us that there are three ways of listening that enable us to understand a person's story and Frank (1995), who encourages us to think *with* stories rather than *about* stories. Anderson and Jack (1991) propose that the first way is by listening to the storyteller's moral self-evaluative statements, which allows us to examine the relationship between self-concept and cultural norms, and between what we value and what others value. For example Sarah (p. 144) shares: *And that I've let him down, that I've let, you know, sort of, not only him but us down and life, society, everything, I just felt like a real failure.* The self evaluation of failure reaches beyond self-concept in the recognition by Sarah that she has failed to fulfill her societal duty to reproduce and she is using this value to evaluate herself in her response.

The second way of listening put forward by Anderson and Jack (1991) is by paying attention to meta-statements, which are places in the interview where people spontaneously stop, look back and comment about their own thoughts or something they just said. This allows the voice of the storyteller to be heard rather than the researcher's own preconceptions and alerts us to the individual's awareness of a discrepancy within the self or between what is expected and what

is being said (Anderson & Jack, 1991). For example James (p. 118) talks about his decision to initiate the cessation of infertility treatment.

And so probably gained some comfort in the fact that I was making ... doing the right thing. ... At least thought that at the time, that that was something I was going to need for me to make a decision to cease treatment.

Initially James talks about gaining comfort in making the right decision but then he stops, and says that he at least thought that at the time, alluding to him thinking that he may think differently about the decision now.

The third way of listening according to Anderson and Jack (1991) is to attend to the logic of the story, in order to identify consistencies and contradictions in the person's statements about recurring themes and the way in which they relate to each other (p. 22). For example: A story told by James (p. 117-118) commences with an account of him acknowledging that the ART process was hurting his wife but denying he was also hurt. Throughout the story, however, it becomes obvious both within his statements and with the display of emotion that he has indeed been adversely affected by the negative outcomes of the ART process:

James: Well this (ART) is hurting her, so I want ... I don't want us to be involved in it. Did it hurt me? It probably didn't ... I was ... um ... I'm a bit disappointed for her, but I was ... I don't know that I felt afterwards ... the failed attempts, the level of disappointment that Rosemary felt. I mean, she's the one that's gone through it and put herself out and had all the blood tests and done all the travelling and ... ah ... inconvenience is probably not heavy enough, but it was ... I mean, it was obviously invasive, but it was more at that level that sort of devastating, which it was for Rosemary. I mean, she'd, I can remember on the hands, you know, she'd have the number of eggs that were to be transferred or something, and ah ... um ... and the next day when ... the couple of weeks after it, you know, when that didn't work out, that's ... (tearful) so ... um. So I guess it was sort of, I mean, motivated by the fact that I could see the pain that she was experiencing with that but not ... I mean, we could have gone a bit longer with

that in hindsight. Because you're a long time without children. (tearful). So my hurt's been around her, seeing what she's gone through and those expectations and then ... and then being devastated by that.

Frank (1995) claims that 'One of our most difficult duties as human beings is to listen to those who suffer' as 'these voices bespeak conditions of embodiment that most of us would rather forget our own vulnerability to' (p. 25). To truly listen to a story, Frank proposes that we think *with* stories, that is, experience the story as 'affecting one's own life' (1995, p. 23). By listening closely to and thinking with participant couples' stories, one way of understanding their stories is presented in the chapters that follow.

Conclusion

The current research is guided by the belief that, as Frank (1995) affirms, listening to someone's story attributes value to that individual. Gathering stories using feminist perspectives enhanced respect and mutuality in the research process. My decision to use feminist perspectives of reciprocity and self-disclosure to inform and guide this research contributed to the collection of participants' stories that are rich in experience. Using the previously described ways of hearing and listening to the stories led to a form of analysis that showed the way dominant stories and positions have an effect on the way that stories are told. The following chapter is the first of three chapters that present the narrative of misguided hope. Chapter Four narrates specifically why participant couples sought treatment for their infertility, their experiences whilst undergoing ART treatment, and the deciding factors that lead them to cease treatment for their infertility.

Chapter Four

TREATMENT HISTORIES

*Ever since I could remember
 I've wanted babies
 I can't remember ever being any other way.
 Some women have that strong maternal feeling.
 Mine was intense,
 But not to be
 When I die and go to heaven it will be my first question
 Why me?
 (Pamela Newman, 2001)*

Introduction

The poetry written by Pamela Newman and displayed throughout this thesis is a source of continual inspiration for me. My initial contact with Pamela was through a third party and came about in the initial stages of my doctoral studies as I was searching for literature. Pamela offered to write some poetry about her experiences and feelings related to infertility and biological childlessness. Reading Pamela's poetry for the first time was both memorable and thought provoking. I recall a variety of feelings and thoughts, ranging from sadness to surprise. Sadness due to the memories this poetry provoked of my own experiences, and surprise that a woman in her fifties was so able to clearly recollect these memories many years after the experiences. I remember being taken aback by the strong remaining presence of infertility and biological childlessness in Pamela's life, as it seemed to reach far into her being, never totally being resolved.

Pamela's story was extraordinary in that she and her husband had adopted three children prior to finding out she was infertile. After their infertility was revealed, she and her husband adopted a fourth child. Pamela and her husband also endured ART in the quest for a much-wanted biological child. As revealed by her moving poetry, ART was not successful in providing them with their most sought-after desire. The following poem illuminates the importance a biological child holds for Pamela:

*On my finger I wear a beautiful ring
It contains five red gems within the gold.
One each for the four children I fought so hard for
Born in my heart, not under it.
The fifth for the child we fought so hard to make.
Always with me, always close,
Always beautiful.*

Like Pamela, participants of this research desired a biological child. Their stories presented throughout this chapter begin with either background information on why they commenced infertility treatment or their experiences during this treatment. The presentation of this information as a beginning serves to set the scene for the rest of the story, highlighting key aspects that enlighten the reader regarding influences that played a part in participants seeking, persisting with, and finally ceasing technological assistance for infertility. The beginnings of the men's stories understandably differed at times from the women's stories, as ART procedures differ between men and women. Also, as treatment for infertility is individual to the couple receiving it, within the beginnings themselves are varying accounts but also many commonalities. For all couples, however, ART was presented as almost a requirement after being diagnosed as infertile, the next step in the pursuit of parenthood, with little or no discussion regarding the alternatives to biological parenthood. The narrative presented combines stories that best

exemplify the dominant stories found within individual transcripts. I acknowledge that each transcript contained many stories, dominant and otherwise, and therefore stories that best represent all accounts of an overall collective story are presented.

The first life plan

Participants perceived their planned or idealised life as very different to the one that eventuated. This is not so remarkable, as life very rarely turns out the way people imagine. What is remarkable, however, is the fact that these couples had not asked for something unrealistic or extraordinary from life. They were planning a family. They had made the commitment to marry, and along with societal expectation they were expecting progression in that marital relationship in the form of procreation. All their lives they had been led to believe that along with marriage comes the responsibility of reproducing and caring for offspring. Sarah exemplifies this in her story:

Sarah (p. 7): I'd always thought, you know, the big white wedding and then the kids and the family, you know, that sort of ... that's how in my mind it all panned out. So I had the big white wedding and that was it. Nothing else panned out as I'd always imagined it. It was just accepted that that's how it would be. It was like a huge shock to realise that it wasn't going to be like that. It was like, wow. But all my life it's been the plan and you just accept that that's how it's going to be. Even when we first got married, I remember we took out insurance policies. This is long before we even started thinking about having children. We made them endowment policies, so the kids would have funds to go to uni or whatever they wanted to do. So we were actually accommodating the fact that we were going to have children, just accepted the fact that that was our given right. And there was nothing you could do about it, it just happened, which was very naive of us... in retrospect.

Finding out they were infertile was a great shock to the couples as they had perceived they would have no difficulty in conceiving. Prior to the time they were

purposely attempting to conceive, most couples were using some method of contraception, further demonstrating their certainty of their ability to conceive a child. Aimee describes her feelings after being diagnosed with infertility:

Aimee (p. 11): I guess I always thought ... well I think like I'd said before,... if I wanted to do something, I'd go and achieve it and do it. Um ... and that was the first real hurdle that I think I've pretty much ever come up against. So it was like hitting a brick wall literally. It was a real..., it was a shock.

Receiving a diagnosis of infertility was the beginning of a non-normative narrative for couples. Their stories were now different to the majority of married couples as they required extraordinary intervention in order to conceive a child. The importance of having children in a marital relationship is illuminated in a study by Perrone, Civiletto, Webb, and Fitch (2004), where the most common family goal prioritised having children over having a good quality of family life. In light of the importance of procreation to a marital relationship, it is not extraordinary that when these couples were having difficulty in conceiving they sought medical advice. However, these couples were taken aback by their prompt referral to ART.

Infertility and the progression to ART

Accessing ART was seen by health care professionals as an automatic progression for those with infertility problems, and was suggested to participants soon after the initial diagnosis of infertility. The idea of undergoing treatment for the purpose of reproduction, however, was not always easy to come to terms with. Andrea tells of her experience when advised by her doctor of the urgency to access IVF:

Andrea (p. 4): And I went to see a doctor here and I had the shock of my life, he started to say, 'oh wow you'd better hurry up, I'm going to get you to IVF tomorrow', and I was just so shocked. Shocked and probably a little bit resentful, I started thinking 'for Christ sake why didn't anybody tell me', you know? And he started to ... seemed to make it sound like this was having to be done straight away. The jump from thinking that you may have a problem to having straight away IVF, for me was just wow! And I couldn't, ... at that stage I just couldn't, I couldn't even contemplate IVF. It was just 'my God there's got to be something else.'

The reluctance to accept that technological assistance was required to become pregnant was apparent in conversations; however, ART continued to dominate options put to couples by health professionals. Anna shares a similar story of prompt access to ART:

Anna (p. 1): Well it started about a year after we got married. That we ... not being successful in getting pregnant. And I've had a history of, you know, a long time in between periods. So, you know, quite a long time. And so I'd only really get about four or five periods a year. And I'd never really had that even looked into. And it's quite funny because, you know, I'd been going to doctors and things like that and never really had anything diagnosed or anything done. And I must admit I was probably one of those women that didn't really put much emphasis on my body or knew anything about anything, any part of my body working. So I went to my doctor and she was great. And ... but she said to me, look we should do some tests. Now I'm going to forget all the proper names for things and whatever, but anyway, what it worked out was that I had something that you'll probably know what it is that ... I forget what it is now. But anyway, I just get ... um ... I ovulate ... I ovulate now a lot more but I wasn't then. I was only, you know, three or four times or so a year. So ... a bit ... probably six times ... I'd get a period every two months. Okay. So I had some tests done and I had low oestrogen, or something ... or high ... I can't remember now. But she (doctor) just said to me given that fact and what it was that if we were trying to get pregnant she suggested that we should go and see an infertility specialist. Smack bang, straight away. Which we did. So I went to IVF.

I acknowledge that some years have passed from the time Anna was first diagnosed with infertility. However, she has very little understanding of what her infertility problem involved prior to being referred to an ART clinic. Anna conveys that she was '*probably one of those women that didn't really put much emphasis on my body or knew anything about anything, any part of my body working*' and when the doctor '*suggested that we should go and see an infertility specialist*' they immediately followed this advice. This indicates that Anna may have simply complied with the advice given to her by her doctor regarding her reproductive health, without adequate knowledge of both her 'condition' and all treatment options available to her. Many years later, Anna reflects on her lack of knowledge regarding her endometriosis and polycystic ovarian syndrome (PCOS):

Anna (p. 15): ... but you know with me I had, ... they diagnosed me with these things. I don't still to this day know whether I got the right treatment for those things. I never got any treatment for endometriosis. I still don't even know what I'm meant to do about that, you know.

The uncertainty regarding whether or not treatment for their infertility was contraindicated to their condition was a genuine concern for some couples. This concern is not unfounded as the lack of knowledge regarding management of diagnoses such as endometriosis and PCOS may have future health consequences for these participants.

Unlike findings presented by Throsby and Gill (2004), where male factor infertility was not acknowledged by either partner as the cause of their infertility, couples who participated in this study shared this information freely. Carl shares the primary reason for his infertility:

Carl (p. 1): But, yeah, we, um, we've been going ... we've been trying to have a child now since, I think it would have been early '96. And try as we might nothing happened. Um ... and so we went in and saw ... we were put onto it by some friends of mine, a bloke I know, [specialist] he's the golden child of infertility from a OBGYN point of view [location]. Um ... and he did tests, a laparoscopy on Aimee and did tests on my sperm and that and realised it was male factor at that time. Um ... because, yeah, I've got taddies that just don't particularly work well. I think of them as Homer taddies, I don't know if you've seen the Simpson's episode when they have a picture of Homer's sperm when they've got his head on it? That's pretty much how I think of mine, they're just running around bumping into each other and doing everything completely incorrectly. Um ... and so yeah, that was decided and so we, I suppose were introduced to the idea of doing IVF and so we went to IVF and did all the counselling and that sort of thing. And off we went.

Being introduced to the idea of IVF was a common and often immediate treatment plan presented to all participants when diagnosed with infertility problems. With ART being so readily promoted in the form of instant referral by health professionals, this presents it as the 'solution' for infertility. Subsequently, this positive portrayal underpins the expectation that ART will provide a successful outcome.

Great expectations

For participants of this research, and for the people close to them at this time, there was an expectation that ART would result in them having a child. For participants, the chance of becoming pregnant through ART was understood on one hand to be negligible; however, their expectation and faith in technology remained. This is portrayed particularly well by Rosemary, who shares her memories of being surprised when hearing of another woman having to endure repeated treatments:

Rosemary (p. 1): So the first day I arrived at the clinic ... these are just impressions ... but I can recall understanding that my chances of success weren't real great. Like, I understood that from the conversation. So it's interesting to me that intellectually you understand things but you respond emotionally differently. So I went to the clinic and we had to in those days walk a couple of blocks to the scan place, where you got your first scan. And one of the sisters said to me, oh [another patient] here will go with you because she knows where it is. And internally I thought, oh that means she must have been through before and it wasn't successful. So I wandered around, walking over, I said, 'oh, you've been through before?' And she said, 'yes this is my fourth attempt.' And it was like someone kicked me in the stomach. And I thought, 'Oh, my goodness', you know? It was interesting, I don't know why I was surprised. But it was like, you've got to go through four times and we're going to have to do this four times!

Not only were the couples' expectations somewhat unrealistic, so too were the expectations of the families and friends of these couples. This is illustrated in Rosemary's story about her first IVF cycle:

Rosemary (p. 1): And my family was all preparing for quads, you know, as they've seen in the Women's Weekly. So you go through your first cycle and it doesn't work and you're not prepared for ... no doubt all the hormones don't help either. But you're not really prepared for the impact, as you know. And I can recall in that first cycle just expectations of people ... like family members and that brought around casseroles and food. I used to have to get up at five o'clock to get to the clinic. It was the only clinic operating for a little while. They'd bring around, you know, were very supportive. And then after the first failure they didn't do that any more. And people didn't talk about it. I didn't worry about (them) not doing it, but it was interesting and sort of a reality check. It wasn't so romantic any more, any of it, you know, it was a bit of a grind.

Rosemary's story also exemplifies societal expectations of ART, which Shanner and Nisker (2001) acknowledge are fed by media reports of positive outcomes, because negative outcomes are not widely publicised. For example, as Rosemary highlights, stories of IVF 'successes' are common in magazines such as the *Australian Women's Weekly*. However, it is not only magazines that are

responsible for implying high success rates for ART. The promotion of ART by not only health professionals, but also society in general, as the most desirable potential solution for infertile couples is evident in all conversations with participants. Contrary to Rosemary's experience of being told of her limited chances of success, other participants' perceptions of what they were told were very different. Some of the women articulated the view that in hindsight, had they been informed of their realistic chances of conceiving and maintaining a pregnancy with ART they may have made different choices. Anna tells a story of the promotion of continued hope throughout numerous procedures when in reality her chances of 'success' were minimal:

*Anna (p.2): So we were about ... by that stage only about six months from me going to the doctor and I was already having things done to me. Which was such an eye opener, because I'd never had, you know, anything done like that before. And that's a pretty strange thing, because all of a sudden there's people looking inside you and they stuck you in stirrups and all these things'd happen. Plus you have really no idea what it is that they're going to do to you. And um so we did all that. And he (doctor) was very happy with what happened but he ... you know, he told me that my left tube was completely grown over and of no use whatsoever and they couldn't do anything to help that. But my right one was ... they got rid of a lot of stuff in there and everything seemed to be fine. And that was, you know, an excellent chance of being able to have some form of IVF and all these different things. So that was great. And so you kind of felt, oh well that's good, that's really good news, you know. Not realising that, you know, again your chances have diminished because, you know, there's all these other things and plus now you've only got one tube and whatever. So ... but you **were** made to feel like it **was** going to happen. 'No matter what, we've done the best job here, we've done', you know ... and it was great that they had but in hindsight now I wish I was told then what my chances were, because as you ... as it goes on in the story, I mean, eight, nine years down the track, you know, they then start telling you ... your percentage chances of getting you pregnant, because they know that they're running out of time. But at that stage I was already quite low on time as well, you*

know, and I may have made other choices, if I had have known what was ahead of us and what the chances were.

The importance of hope in ensuring further treatment is obvious in Anna's story, when she describes the positive attitudes imparted by ART clinicians in the initial stages of treatment. Stories of building hopes are not exclusive to women throughout ART but are also evident in men's stories. Greg recounts being hopeful that medical intervention would result in a positive outcome:

Greg (p. 10): There was always the hope that there would be this medical solution to the problem. And through that process, I mean, the thing is we were encouraged, we did have feelings of hope that things would work. The thing is if Andrea did produce our embryos and they were good quality and things like that. It was looking positive at stages. But then things started to go haywire half-way through that suddenly ... you know, as you know yourself, it's sort of a roller coaster ride through that process, the thing is that you have this sort of a build-up and the expectations of hope almost like you have created things yourself and you know babies are growing and that kind of thing. And you approach it as any sort of pregnant couple would I guess, and that is you're ... oh, well potentially pregnant couples, you go through the game of playing we're going to be parents kind of thing. Things are growing inside you.

The definition for infertility and the criteria for entry into ART programmes is not only the failure to achieve a pregnancy after twelve months of unprotected intercourse, but also the inability to continue pregnancy to a live birth (Gibson & Myers, 2000). This definition positions couples as failures at reproduction, but ART clinics use these same criteria to claim a success. Women who have conceived but been unable to continue a pregnancy to a live birth prior to seeking treatment are labelled unsuccessful. However, if the same women accessing ART conceive, this may be counted as a success for the ART clinic. This representation of 'success' is exemplified in Anna's story:

Anna (p. 2): And then, anyway I did get pregnant. Um, I think I had another one of these laparoscopy things or whatever he did. He specialised in something that not any of the other doctors were doing. And he'd go in and he'd blow you up inside or something or whatever, anyway and clear everything out. So, um, and I've thrown all my files away, so I can't tell you exactly what all these things were. But he then said, um, so okay, so I had no idea ... I was on Clomid. We went away on a holiday, we went sailing. We then drove back through [location] and visited my sister, and I was sick as a dog and had no idea, got back home and I was pregnant. Um, and ... but by 12 weeks I had a miscarriage, so which was very, you know, sad obviously. But he (IVF doctor) kept saying it was ... it was his success. Because I was on Clomid and he'd done this thing, he'd cleaned out the tubes and all these kinds of things. And ah thinking ... and I kept thinking to myself, well you know, I'm not sure how that equates to that, but okay if you want to class that as your success ... Again, it's something that they probably put in to figures, you know, they achieved a pregnancy. And I don't know how he thought that he was ... I can't remember ... I'm fairly sure I'd been on Clomid, but I was actually off then. And then ... but he had done this thing where he'd cleaned out the tubes and he put that down obviously in his own records as being that was a success for him. So it wasn't a success for me, I can tell you, because I was pretty devastated.

Apart from the issues surrounding varied definitions of success and failure in this story, Anna's obvious lack of understanding of the procedures she endured raises issues regarding how procedures are explained to ART patients. Rosemary also articulates a sense of failure after having an IVF miscarriage:

Rosemary (p. 18): And I recall after the D&C the next morning ... um ... the nursing sister said to me, your husband's coming up to see you. And it was this really funny thing and I said, well I don't want to see him, I don't want to see anyone, okay, just close the door when you leave. And I'll never forget James coming in with a great big bunch of flowers and that's the last person in the world I wanted to see. I think because I felt like I'd let him ... failed him too, like you feel like you're the one that's lost the baby because it was inside you and it's pretty hard not to feel like that. And he was just so positive, I mean he's just a very positive person. I just couldn't sort of resist that, I mean I got out of bed and

I came home and ... but I literally didn't want to see him, I didn't want to see anyone.

A disappointing experience

The process of receiving ART was dominant in conversations and vividly recounted by participants. Very few of these stories had positive undertones, most revealing negative experiences encountered throughout treatment. Aimee shares her disappointment regarding attitudes of staff at the ART clinic:

Aimee (p. 2-3): ... they (ART clinic staff) weren't very understanding, it was like we were a bit of an inconvenience almost. Um ... and actually before the egg pick-up I actually had to go on Heparin and I had to organise all that. Because they found I had some antibody or something that causes clotting or sort of thrombosis and all that sort of thing. So I had to go on Heparin and I'd never used it before. And the nurse who was supposed to take us through it, basically just gave me the needles, here you go and ... it was lucky I sort of knew, I'd just done pharmacology and we'd done needles and how to give injections and stuff. But she just sort of didn't ... wasn't interested in teaching us, and I just thought that was really ... both from a nursing point of view and a patient point of view, I thought that was just disgusting and oh just really disappointing. Um ... and then even our doctor ... um ... actually I left one thing out, I was diagnosed with endometriosis at ... um ... just over 12 months ago. So before we'd done this last stim¹¹ cycle and everything. And we were starting to get a little bit, I think, disappointed with our doctor as well, who we'd had the same one the whole way through. Um ... he sort of didn't believe that the endometriosis was a big deal. Um ... whereas I sort of thought it was a big deal, both ... I mean pain-wise and everything, and how I was feeling ... health ... you know, within myself. And for the infertility. Um ... and he just sort of kept saying, oh it's nothing don't worry about it. And then after the last stim cycle all my symptoms came back. I'd had a laparoscopy and had it ... had all the endo¹² cut out and everything. And as soon as we did the stim cycle all the symptoms came back. He ... I went to see him about it, and he said, oh it can't be the endo because it doesn't come back. And so that was just another reason ... another reason to sort of, that really turned us

¹¹ An IVF cycle that includes ovarian stimulation.

¹² Abbreviation for endometriosis.

off the whole IVF thing. We just really ... we'd had enough of the whole thing, the doctors, the ... being on the drugs and ... yeah, just, oh yeah. It just really a disappointing experience, that last one, so ... I don't think you could pay us enough to go and do it again. They'd want to come up with something a hundred percent guarantee that you're going to get pregnant before we'd even consider it, I think. And I don't think that's going to happen, so ... Yeah, it was a shocker.

Unlike their wives, the men in this research were not subjected to invasive procedures. Embarrassment was prevalent when referring to their physical contribution to the ART process. Similar to men highlighted in studies by Carmeli and Birenbaum-Carmeli (1994) and Throsby and Gill (2004), the men who participated in the current study admitted to experiencing embarrassment in producing a semen sample through masturbation. However, this personal discomfort at providing the sample was considered as trivial by the men, in comparison to their wives' experience:

Alex (p. 4): It's just a bit embarrassing having to take your little bottle into a room and read your man magazine or whatever they were. But you think, oh well, everyone else's done it. And no one took any notice of you anyway. So, oh well that's all right. And everyone just did their thing and everyone said, right, fine, you know. It was all very, who cares? That was a pretty ... but you think not as bad as what the girls have got to go through. A few minutes here or there ...

Carl elaborates on what he witnessed his wife go through during an IVF cycle, discounting any embarrassment that he may have felt:

Carl (p. 3): And so we went through it, and it just, the damage it did, and as soon as she had the stim cycle of course it just flared beyond belief. It just ... the hormones just played havoc with her, made her uncomfortable and painful. And we went to the ... you know, she had to see gastroenterologists to sort out her bowel, because her bowel had been damaged by the endo. And so she's gone through hell, you know. I mean, my whole contribution is to come in a cup and that's all I've ever had to do. Um ... whereas she just gets poked and prodded

and damaged and it's just ... in the end it gave me the shits. I just started to think, is this worth it? Is it worth watching?

The acknowledgment of the inequality in the physical contribution of ART between men and women was paramount in conversations with participant men regarding treatment. From the perspective of the men who shared their stories, ART was cause for great concern. Whilst women acknowledged the hardships encountered and endured whilst undergoing treatment, their focus of 'achieving' a pregnancy was dominant. For the men, however, watching their partner being subjected to what they considered as harmful, damaging and even life-threatening procedures was a source of great angst.

Watching the discomfort and the damage

From the literature pertaining to men and the importance of parenting to them, such as that by Greil (1991) and Van Balen and Trimbos-Kemper (1995), it could be surmised that becoming a parent is not as important for men as for women. However, in the transcripts in this research this was not the case. The difference was that the men did not want fatherhood at the expense of the health of their partners. Participant men held grave concerns for their partners throughout the course of the various assisted reproductive treatments. Greg expresses these concerns when talking about an incident in which his wife was put at risk through ART treatment:

Greg (p. 11): She's on a monitor for half or a full day and things like that. And it just ... it seemed that the cerebral idea, the intellectual idea of science producing a hope or giving a hope and producing a result, when you actually see what your spouse has to go through, you know, I mean it's frightening. It really, really is frightening, so primitive in a way. And this sort of started to build in my mind about two-thirds of the way through, this is not going to work. You know, you can't make her go through this process. It ain't natural. And then it just got

progressively worse. Andrea suffers from low blood pressure and the thing is that they overreacted to that, she was kept in hospital, she was given, I think, at one stage she developed an infection after a transfer, one of these sloppy transfers. And they gave her antibiotics, and that's it! That was the end of it. It was devastating! Andrea was just shattered as a result of this. And that pretty well ended it. It wasn't the fact that this wasn't getting anywhere.

Here Greg talks about the hope technology instils versus the reality of treatment.

The statement by Greg '*you can't make her go through this process*' alludes to him not wanting to see his wife go through this '*frightening*' and '*primitive*' process for purely a *hope* that he will become a father. Unlike findings from other research such as that by Throsby (2002), where participants constructed IVF as essentially a natural process, participant couples of the current study considered ART to be just the opposite. Greg stating '*It ain't natural*' corresponds to the common opinion expressed by men who participated in the current study. Watching their partners go through a series of what they considered unnatural procedures often led to feelings of hopelessness and a loss of control in the entire process.

As with all men who participated in this study Greg rapidly lost belief in the ART process, often viewing the staff who administered treatment as incapable or incompetent. This is evident in his story where he expresses dissatisfaction regarding the lack of attention to detail given to the embryo transfer process, which he refers to as '*sloppy*', resulting in his wife enduring unnecessary anxiety and discomfort:

Greg (p. 10-11): But where it starts to come off the tracks was this, was when one process completely failed under circumstances, which we're still not sure of. We had suspected that it was a sort of a laboratory fault that they'd done something, because it was just too radically different to the pattern that had been

established. The thing is that Andrea was producing sufficient high quality eggs that transferred okay. And it seemed to be that the process that was coming off the tracks, that is, that the ... there was that example which was shattering for us. We didn't even get to square one kind of thing. And secondly was when in fact the transfers occurred there was always difficulty in the transfer in Andrea's case because in fact she had I think a cervical configuration that in fact wasn't quite normal. And we've insisted ... and part of the process was we actually had to monitor the medical ... you had to actually tell them what ... 'last time this was what was detected, this was what they noted, please put it on file so you know next time.' And it seemed that he never ... there was never any succession. It was always ... every time was like the first time and they didn't seem to learn from the previous occasion. And this just increased tension and anxiety. And then also seeing your spouse go through that process was devastating.

Greg highlights the lack of care taken by the ART service when they continually neglected to take into account Andrea's '*not quite normal cervical configuration*' which made ET difficult. The lack of continuity and individualised care illustrated in Greg's story contributes to the overall negative impression of ART services conveyed by participant couples.

Carl expresses guilt that his partner endured multiple treatments and procedures and perceives his contribution to the process as minimal. Again the portrayal of ART is one of damage and destruction:

Carl (p. 6): Um ... it was a very powerless thing ...for me to watch. Because all I could do was support and help her through it and help her through the pain and discomfort that was inflicted on her. Um ... from the male point of view, I can only talk from my point of view, um, depending on what sort of person you are I suppose, and how much you actually give a rat's ... um ... IVF treatment or infertility treatment is still, I think, very focused on female. Um ... the ... and from a certain point of view, fair enough, ah, because most of the hard work gets done by the, um, the woman. And it sort of leaves you there watching this abuse of the person you love more in the world than anyone else and not being able to do anything about it and actually encouraging it. Or sitting there saying, well to do this we're going to have put you though this, gee, you know. But it's easy for me

to say, because it's not me, I mean ... you know ... my brother, when he went through, because they went through some IVF and it was a complete waste of time, they got pregnant anyway. Um ... yeah, he had to have a testicular biopsy and that sort of thing and you know, at least he got a bit of pain inflicted on him to go through the process. Whereas I never did ... um ... so, yeah for me it was sort of a real helpless ... you know, people said, oh but you're there you're helping through, but I'm not actually experiencing it, I'm not doing anything apart from standing by watching. And I don't like that, because I like to be more pro-active in things that are happening around me and that was never an option.

The physical contribution by men in the ART process is very often limited, with women's bodies continuing to be the focal point of treatment regardless of the source of infertility. This inequality in treatment serves to position men as outsiders or bystanders to something that they feel they are integral to. When asked whether he would have felt better if he had endured invasive procedures also, Carl gave the following reply:

Carl (p. 7): Probably, yeah. Um ... maybe that's just a psychological thing because there was no physical impact on me. Um ... there was emotional impact, I'll never deny that. Um ... it was quite damaging at times. But there was no physical procedure done on me, there was nothing actually done. There was talk of it initially but it was ... turned out they didn't need to they could use ICSI and pick out the correct, the best sperm and that sort of thing. Because ... um ... my count wasn't that bad ... it wasn't good, but there was certainly enough there to be usable. So, yeah ... that was the issue I had ... was sort of yeah the sitting back and watching Aimee go through all the discomfort and the damage and that and me just sort of ... you know, what's my input, you know, I can support and I did that, but, um, yeah you do feel like a bit of a fifth wheel at times in the whole process.

The lack of inclusion for participant men in ART processes contributed to feelings of helplessness while they watched their loved ones go through invasive and potentially dangerous procedures. Although acknowledging the emotional impact of IVF was '*quite damaging at times*', Carl's story conveys his feelings of not

'pulling his weight', of not contributing enough to the point where he would have preferred to go through these procedures rather than have to watch his loved one carry the burden.

Contrary to the other men who participated in the study, Derek actually felt included in the ART process by providing support and assisting his partner with the administration of injections:

Derek (p. 6):... and we did everything at home, right, and so I felt ... and when she would have all these ups and downs ... and highs and lows because of all the hormones and injections every night ... I can't remember whether it was in the morning or night, at one point it might be several injections for month or day or weeks I can't remember and we just had to find a different spot and all that. So we did everything together and um ... and you know, had to prepare all the syringes and then when she got sick I was there and when she had miscarriages I was there and ... I was there all the time, so I felt part of it in that respect and as much as possible.

Derek's sense of inclusion in the process stems from administering treatment to his wife as well as playing a supportive role through times of great difficulty. He does however concede with the concluding comment '*in that respect and as much as possible*' that apart from an essentially supportive role, participation in the process was not possible.

Alex articulates the sense of hopelessness he felt at not being able to 'fix' things for his wife:

Alex (p. 6): Oh, yeah, that's probably the worst part, as I said before, just you can't really do much about it. And sort of sitting around and not being able to do anything about something is really hard. So, yeah, seeing your partner, it's the same as seeing your partner sort of in any horrible situation, you want to jump in and fix it all up and carry on. And these sort of things and psychological things you can't. You can't. You're all a bit of awash, oh bugger, you know?

Wanting to problem solve, according to Badr (2004), is exemplary of men's typical reaction to many problems. Thomas (2003) suggests that the compulsion to 'fix' things is an initial attempt at gaining control and if the attempt is unsuccessful results in anger. There is, however, no quick fix solution to infertility, even with the assistance of modern technology. Carl tells of the anger he experienced throughout the ART process:

Carl (p. 7): I became very angry, very stressed. Um ... and it's a genetic thing, males in my family have a fairly decent temper at the best of times. And it seems the more we, um, with each successive generation it seems to distil down to a slightly more angry aggressive form of temper. And I've never had a huge issue with it. Um ... until we started this. And it got to a point where ... um ... I was very, very angry. It rarely, if ever, presented itself at home. Um ... it normally presented in situations outside of here. Now whether that was because I wouldn't allow it to present here or whether the triggers just weren't in this environment. I don't think they were. Road rage, things like that, like wild road rage. Um ... it got to a point that ... about April last year ... um where I came very, very close to assaulting a client... um and I actually took myself off the road.¹³ I went and saw peer support and went and saw my boss and said, 'this is what's happened, you know, I need to stop, I need to stop right now.' And they're well aware that I was on IVF and they were extremely supportive. That's one thing my work place does very, very well. Um, and so they gave me ... I was four weeks away from leave and they said, 'look take from now off'. So they gave me an extra four weeks off. Um ... but yeah the greatest ... the most ... the best presentation of it with me is the anger. I really ... um ... and whether it's the frustration of just, yeah, it's just always watching this happen and not being a hundred percent part of it, I suppose.

Carl describes anger building up over the duration of many cycles of IVF in which he consistently felt excluded from the process whilst witnessing his wife being subjected to invasive procedures. The lack of control in this situation lead to

¹³ Driving is a requirement of Carl's job.

exhibitions of anger and was further fuelled by the knowledge that his wife was undergoing treatment for something that *they* wanted and for which he could only minimally contribute.

The catalyst to ceasing ART

The catalyst to ceasing treatment was, for all but one participant couple, a negative experience associated with ART. Some participant couples ceased treatment immediately after such an experience, whilst for others it served as a turning point in their expectations and faith and hope in technology. Greg shares his reason for ceasing treatment:

*Greg (p. 11): What really ended it for me, and possibly for Andrea, was that, I'm not sure these people know what they're doing. They're hurting her. And **nothing** but **nothing** is worth, you know, your spouse being hurt, or **losing** your spouse because of this process. But who knows what the long-term consequences of this are. And to this day I'm still afraid that whole process is going to come back and bite us at some stage. And that was really it, that did it for me, seeing her in a hospital on drips under those sort of circumstances where in fact, you know, again we'd got back to this life-threatening situation. I'm not going through this again. I don't want to see her go through this again.*

As well as being concerned regarding the immediate health of his wife, Greg raises issues of possible long-term implications of ART treatment. Whilst the women seemed less concerned regarding the treatment they were receiving and the impact it had on their immediate health, their view of ART was altered by other significant events. Rosemary shares her story of a traumatic miscarriage and articulates how this changed her view of ART:

Rosemary (p. 2-3): I had my pregnancy confirmed on 19 December, I remember that. And over Christmas, on Christmas day we went to a restaurant and I spotted a couple of times. And I can remember panicking. Sitting there with my legs, feet up on the chair opposite me. And I went to the bathroom there once,

noticed I was spotting. Sort of just, my heart stopped. And then I thought, I could always ring the registrar on call. And I thought, what's he going to do. He'll only tell me to, you know, rest or something and that's what I'm doing. So I had a few little sort of scares like that but nothing particularly dramatic. It would just settle down. But then at 14 weeks I can remember that morning feeling very depressed for no reason. It was a Saturday and at about five o'clock or six o'clock I had some pains, which I didn't like the sound of. And I knew that wasn't a good thing, because I was cramping. And then I had begun bleeding a little, but not much again. And then I get the early equivalent of your waters breaking happening. I can just remember this expelling. It was really odd. And it was just clear liquid. And then the pains got really bad and I was bleeding and James rang the hospital and they said, you've got to get her in straight away. And he told me later, they said, look ... and I'm saying from the couch, I'm ... I can have a miscarriage here as well as in hospital. I'm not going to go anywhere. And they apparently said to him, you've got to get her in here now, we don't know what we'll be able to do. We can't do anything if she's there. So we just got some towels and went into [the hospital]. And it was just all ... difficult. I remember getting out of the car – I had my nightgown on – I remember getting out of the car in my dressing gown and there was an ambulance driver there and as soon as I stood up, I just ... it was like someone turned on a tap, you know, there was blood everywhere. And I'm having the towel ... it was just socially, the most dreadful situation, you know. You're totally helpless, you don't know what to do and the ambulance man was I don't know who it was but he was really nice. He just walked over and said, you know, 'what ever's wrong?' And I just said, 'I think I'm having a miscarriage' ... I was trying to give him information ... 'I think I'm having a miscarriage and it's an IVF baby.' And he was really sweet, he just picked me up, towels and everything and took me in and put me on a bed and ... [that was] where I lay for several hours having a few people examine me. They'd obviously decided, I guess, that there wasn't much they could do. I tried to get the doctors that I knew from the unit. I listed off about eight and none of them were around. When they heard I was [IVF Professor's] patient, they sort of became very attentive. And ah ... but I just didn't want a doctor I didn't know. I was like ... I said, 'it's not that I don't trust you, I just want somebody I know.' I was used to being a private patient and ... yeah that was an interesting ... just experience in a public hospital setting. And um ... yeah ... at some point the doctor there came in and she said, I need ... she had a speculum and a dish ... and she said I need to examine you. And I said to her that the speculum you ... 'I

don't want you to hurt the baby.' So it's ... I mean I knew that ... like I was ... I think I was just stunned. I just didn't know what was happening. And she said, 'I just need to use it and I may need to take some material out.' Because at some stage I said to them ... I called them in and I said, 'look I feel like I'm about to ... um ... to go to the toilet or something, I just feel this real sort of strong ... I just can't understand it.' And she said, 'look I think some' – she used some euphemism – 'some placental material or something has come into you, through your cervix or something,' I don't know. And ah ... and then I'm sort of realising what was happening. Yeah ... and then I watched while she took my ... what was left of my baby ... out in pieces and placed it on a pristine linen towel in a stainless steel dish. And that will never ... I will never forget that. So when people say to me later ... I had people say to me, sort of a year later or something, you were really lucky you knew you were pregnant. And I say, I don't think so. I just don't ever want to have my hopes dashed like that again. So even though I guarded them very carefully, [we] went through another couple of cycles, another four.

The importance Rosemary placed on her pregnancy is evident when she refers to it being *an IVF baby*, which differentiates her pregnancy from others that are naturally conceived. The reference to IVF hints at her pregnancy being more special, one worked harder for, one more worthy of special treatment, and recognition of the difficulties encountered to procure it. Understandably, the loss of this pregnancy impacted greatly on Rosemary's perception of ART.

James identifies the catalyst to him wanting to cease treatment as being witness to the suffering of his wife throughout ART procedures and the impact of treatment failure. Burman and Margolin (1992) acknowledge that spouses may become more supportive when the well-being of their partner is threatened. Although making the decision to cease treatment, James also expresses regret and alludes to him making this decision prematurely:

James (p.1-2): Well this is hurting her, so I want ... I don't want us to be involved in it. Did it hurt me? It probably didn't ... I was ... um ... I'm a bit disappointed

for her, but I was ... I don't know that I felt afterwards ... the failed attempts, the level of disappointment that Rosemary felt. I mean, she's the one that's gone through it and put herself out and had all the blood tests and done all the travelling and ... ah ... inconvenience is probably not heavy enough, but it was ... I mean, it was obviously invasive, but it was more at that level that sort of devastating, which it was for Rosemary. I mean, she'd... I can remember on the hands, you know, she'd have the number of eggs that were to be transferred or something¹⁴, and ah ... um ... and the next day when ... the couple of weeks after it, you know, when that didn't work out, that's ..(tearful) so ... um. So I guess it was sort of, I mean, motivated by the fact that I could see the pain that she was experiencing with that but not ... I mean, we could have gone a bit longer with that in hindsight. Because you're a long time without children. (tearful). So my hurt's been around her, seeing what she's gone through and those expectations and then ... and then being devastated by that. (p. 3) I think at that stage too, leading up to cease treatment, it was to do with view on life, because we were involved in, and still are, in Christian things. I think there was a, there was a... in a traditional sort of Christian way thought that as the head of the family that it was my responsibility then to sort of take control of this and to act on it, therefore I needed to make the decision. And so probably gained some comfort in the fact that I was making ... doing the right thing. ... At least thought that at the time, that that was something I was going to need for me to make a decision to cease treatment.

Anna's story is also about the loss of her pregnancy although circumstances were very different. The story begins with Anna being advised that her oocytes were of such poor quality that it was highly unlikely that they would ever conceive a pregnancy. At this stage Anna was advised to ask a family member to donate an oocyte. A close female relative, whom we will refer to as Beth, agreed to be a donor and to go through the process of oocyte stimulation and collection. The donor oocyte provided by Beth, and Derek's sperm resulted in good quality

¹⁴ It is normal practice for a member of the ART team to write the number of oocytes collected at pick-up on the woman's hand so she is aware of the result immediately after recovery from the anaesthetic.

embryos. Anna had two of these embryos transferred to her uterus, which resulted in a pregnancy.

Despite the discomfort of the continued administration of hormones via injections and pessaries, necessary to maintain the pregnancy, coupled with body changes associated with pregnancy, Anna was ecstatic at being pregnant. She had all the tests recommended by the IVF clinic in order to monitor the baby she was carrying, and until the recommended amniocentesis was performed at 17 weeks gestation, all test results had been normal. The results of the amniocentesis were delayed and when the results were eventually available, the tragedy began to transpire. Very little explanation was given to the couple at an urgent consultation with her obstetrician, and they were referred to a larger hospital for confirmation and further interpretation of the results of the amniocentesis. The appointment with the larger hospital was not for two days, in which time the couple and Beth had to have blood tests. All three of them were required to attend the appointment.

Anna shares her thoughts and feelings over that two day period:

Anna (p. 9-10): ... so all that time we know there's something wrong, we know it's something genetic, but we don't really know exactly what. We kind of know that it's not good, um, but here's me thinking, oh ... he hadn't said Down's Syndrome or anything but here's me thinking that. I know that would have absolutely worried Derek to ... it wouldn't have bothered me at that stage, you know, I was not ... I was thinking I was still having a baby and everything was fine and I'd seen it, and you know it was all ...

This excerpt confirms the bond that Anna had already formed with her baby, in part enhanced by visualisation of the foetus on ultrasound. This resonates with Sandelowski (1988) who presents the view that procedures such as ultrasonography and amniocentesis enhance maternal attachment to the foetus. Anna's bond with her baby commenced much earlier than usual, however, as

couples undergoing ART are given the opportunity to sight their embryos with the aid of a microscope prior to embryo transfer, thus enrolling them in the technology (Latour, 2002) and in the pregnancy earlier than couples who do not access ART.

Whilst Anna was slowly coming to terms with the realisation that her baby had some type of genetic disorder or problem, she was totally unprepared for what was about to be revealed at the appointment with the genetic specialists:

Anna (p.10-11): So we went into the [public hospital] and it was disgusting and it was like just, you know, a big waiting room of all these women who were pregnant and I am too but I'm there, and you know that we're ... this area we're going into is where there's all troubles. Because everyone who's walking out is crying. Which was just the most awful thing. So Beth is there with us. And we've gone in and there's just four men, you know, with white lab coats on and they were just awful. I don't think they meant to be awful, I don't know how you can tell somebody the news that they're going to tell you, but it was just awful. And so we were there and they got this board out, this black board, um ... because I'm just crying of course, and just ... unstoppable crying. Because they had already said that, you know, the baby was not going to live. And ... that she was alive ... but there was all these complications, and they started to go through. But they said, 'let us explain.' So these guys are scientists, right, so there was a counsellor in there, I think, but I don't think she was doing much, because I think she was just as astounded, anyway. This was a very unusual case. So then they got out, do you know Cuisenaire¹⁵ (rods) that you used to have at school? They got out this, they had this blackboard there, and they said, 'this is your baby.' And I just remember saying, 'no, no, Cuisenaire?', you know it was really silly, but it was just like ... 'These are the ... um, the genes that um, whatever. And ... the chromosomes, here's all the chromosomes, this is your baby'. And they said 'this is what happens for, you know, a Down Syndrome baby', you know, and they showed the extra one at the end, or whatever it is. And it was right down the

¹⁵ Cuisenaire rods are a set of rods of various colours and lengths representing different numbers, used to teach arithmetic to young children (Butterfield, 2003 p. 406). In this story, they were used to illustrate chromosomes.

scale, and this is your baby, and they were doing all these things. And then all these chromosomes at the beginning and in the middle and all these things were all mixed up and some split into three and they were doing ... this is three now and this one's gone double. And this one ... there isn't one there. It was awful, it was awful. And I was just crying. Derek's listening, of course, because he had to make sense of it and ... but he's going through it too. And Beth was in tears. Because of course she then blamed herself, you know, she's blaming herself that this is, you know, it's her fault. And they're saying, this is a very unusual ... this is like a one in 20 million or 10 million, or something like that. We've not seen this before, they're saying. We've sent it off to ... who cares, you know. 'We've sent it off to some French genetic register.' 'I don't care, I've got a baby', you know? and ... oh, it was just devastating. So, but I'm saying, 'but what does that mean?' And they said, 'well you know there's a number of options.' There was a counsellor there, that's right, cause that's when she stepped in and said, 'there's a number of options and ... whatever, we'll need to talk to you about those.' But, you know, you can either go full term or you can have whatever they call it, it's not an abortion, but virtually it is. But you have the baby, but you know, she's not going to be alive basically. So that was pretty incredible because I hadn't even thought about that. Because I have a baby and they're saying that virtually I had to, you know ... the baby was alive. But I had to do something to the baby, I had to have the baby now, which was way too early. Um, or I could go full term and they then ... so for the next week ... we had to go through this process of them explaining all these different things, that, you know ... so ... We had to be absolutely sure that they hadn't made a mistake, but how to do that?

Anna acknowledges the avoidance of the term 'abortion' by health professionals in this circumstance, thus sanitising this termination of pregnancy. Anna's confusion regarding the explanation given to her by the scientists is evident in her story. Further, while she is in this state of confusion, she is forced into a position of making a decision about the future of her pregnancy:

Anna (p. 11-12): Anyway we had to go back into the [public hospital] the following week to have the baby and there was a number of options about that ... Because, as I said, if I go full term the baby could die anyway because I was off the drugs (IVF treatment) by then, so there was nothing keeping the baby for

long. They kind of said that the reason why it continued on was because of the drugs (injections and pessaries supplied by the IVF clinic), so she might not have lived anyway, I might have had a miscarriage earlier on if I hadn't have been on all those drugs that I was on. So ... um, anyway they ah ... we had to go back in. We had to have the baby and it was just horrific and you know.... so they induced me. Um, at the end I decided at the eleventh hour that I didn't ... I said I didn't want to see her and that at the end they did something where they could knock me out, and I didn't have to actually physically go through the last bit, which means that ... I think they, I think they sucked her out, I don't really know, I don't really want to know. But I know that if you do it that way then it's better not to see them afterwards. I was worried about seeing her anyway because ... I just wanted to imagine her the way ...

The mere presence of a pregnancy is counted as a ‘success’ for the purpose of many ART clinics’ statistics. Furthermore, as the nationally accepted definition of ‘success’ for an ART cycle is a ‘live birth’, further defined as “a birth in which a foetus is delivered with signs of life after complete expulsion or extraction from its mother, beyond 20 completed weeks of gestational age” (Bryant et al., 2004, p. 31), had Anna’s baby shown signs of life it may have been deemed an ART ‘success’.

This tragedy led to the break down of Anna and Beth’s relationship, meaning Anna’s distress was two-fold. Not only had she lost the baby she and her husband had craved for many years, but lost a functional relationship with Beth as well. They were given no indication that there could be a negative result such as this or any warning about the impact that failure of the donor oocyte may have on their relationship. The ART clinic not only failed in their duty to support Anna and her husband but Beth as well, who was also considered a patient at the clinic. Contributing to Anna’s anger was the fact that the donor egg was not subjected to any genetic testing. What made accepting this fact more difficult for Anna is that

the entire ART process is so technologically focussed from the outset, but something that impacted so greatly on their lives was seemingly considered unnecessary or unimportant:

Anna (p. 7): It's technology all the way, so why not at that one spot just before they're going to transfer the eggs, why they don't ... I can understand that they want to be as delicate and as gentle as possible with things, but they're doing it to choose the sex of babies these days. I can't see why they ... because they would have been able to tell apparently, um, that there was a problem with the eggs and with our family. So ... and this is where it all started. (p.11): Why my other two pregnancies failed could have been because of that (genetic problem). And probably ... and I might be, even in myself, I know that this is Beth's....Beth's ... even with my eggs and my situation, I probably, you know, I have it too. And it's (genetic problem) in our family. And they just said, that from that point of view that could have been the case. And, you know, I wouldn't have ever dreamed of having a blood test to find out that that's why ... and who would, if you have a miscarriage you have a miscarriage and you're on IVF and they tell you that that's a possibility anyway.

As well as the absence of genetic testing, Anna maintains that no family history regarding reproduction was taken, which is significant as her mother had four, and her grandmother about seven, miscarriages. Anna felt that due to her family history, coupled with her own history of miscarriage that further genetic investigation was warranted. She talks about the simplicity of the test that could have determined the genetic defect carried by Beth and discusses the impact that the experience has had on their relationship:

Anna (p. 11): So that's how they found out that it was Beth, that the problem was there. That's what I'm saying about the blood test, that the genetic defect was there, they found it in the blood. So they would have been able to do that at the beginning, and they didn't test for genetic defects, they tested ... they test for HIV and whatever else..., So we had that to go through, and Beth was just devastated. We were close but we're not any more. It's almost like this, um, unwritten thing ... we just ... we just don't talk about anything on any level any more ... any

depth, we have no depth. We have ... it's like it just alienated us. I don't think ... I don't think it was ... I don't think it's been anything that we ... with ... we don't blame each other for any part of it, it's just that we don't know how to deal with it.

Due to the fact that the pregnancy was conceived using a donor oocyte, this tragedy had a huge impact on more than the couple. Beth was also greatly affected. Apart from shouldering the guilt of feeling responsible for this catastrophic event, Anna reported that Beth was also left wondering if she had inflicted this chromosomal abnormality on her own, existing children as well. In addition to damaging their relationship, this tragic series of events had serious implications for Anna's entire family as their biological flaw had been revealed:

Anna (p. 12): Um, the doctor in the hospital ... at this stage too, we'd not had any contact from anyone at IVF, my nurse,... my obstetrician ... he'd actually dumped me. One of the reasons I found out later was that ... um, there's only ... the [public hospital] is the only place that does this. And the [private hospital] being kind of more religious kind of hospital, um, he ... it was not ethical for him, so it's one of those things that ... I don't know what you're meant to do ... continue on, knowing that your baby's, you know ... I mean the things that she had are very ... like a brain that was nothing and half a heart and one lung and I mean, I justify it that it was the right thing to do. But anyway, as I said, if I had have managed to even go full term with her she would have died at birth. They might have been able to put her on a machine or something but there wouldn't have been any hope. You have to trust in ... in them saying that too. And up till then I didn't have ... because of that last process I didn't have a lot of trust at that stage. But you actually do have to trust.

Anyway, we had a great doctor at the [public hospital] who I'd never met before, he's the only doctor who did this type of thing. And the nurses were just gorgeous in there. And so the day was awful, because it was a whole day in hospital, early in the morning and out that night. Um, we decided to leave, because I didn't want to stay in there, so checked out at about midnight or something and went home. But, they'd been great all day, anyway he (the doctor) was lovely, he was in with me nearly all day until I went in and then they knocked me out, which was

good. And, um ... but I still had to go through labour, so you know, you ... so .. and that was kind of hard. And anyway, so he ... so I went home and obviously it was just devastating. But you know, they had a network, so the hospital called me ... [public hospital] ... and they've got a counsellor so ... I couldn't quite understand, you know, I'd not heard from IVF, I'd not heard from [IVF specialist], I'd not heard from anybody ... still. Um, I don't remember much of the day in hospital, I just remember that he (the doctor) kept coming in all the time and holding my hand and Derek was there the whole time. Weeks later ... or a couple of weeks, a week later he (the doctor) called me and he basically ... he called me at home and he was really good, you know, and said how was I and all this and what's been going on. He really thought I should go and see the counsellor again, um, asked me if I'd heard from any of my doctors, other doctors, and I said, 'no, nobody.' He continued to ring for the next four or five months, you know, once a month. He was lovely.

The complete absence of ART staff in this whole tragic experience was inexplicable to Anna. She had been attending the facility for many years, had been allocated her own specialists and case managers with whom she felt she had built up a rapport, and now, when she needed assistance to make some sense of what had happened, ART clinic staff were conspicuous by their absence. This lack of contact by clinic staff, Anna felt, devalued her as both a patient and a person. She expected support, as she believed that ART was responsible for what was occurring:

Anna (p. 13): But that was it. I never heard from ... I never ever heard again from IVF, [the IVF doctor], from my nurse, nothing. And it still absolutely bothers me, from the point of view that they didn't even ... number one from the compassionate point of view, like to see how I was. You know, because I'm a patient. I thought I was, but I thought I was a person too.

Anna's story concludes with the funeral of her baby:

Anna (p.12-13): So we went into this ... met with a lady, (public hospital counsellor) who was really nice but you know she had no idea what was going on ... I just cried the whole way through and they told us the following day or more

they would have a service ... we had a ... not quite a burial but it is. They have a ... a joint kind of ... I was 21 weeks, so I was at the time where you have to register it as a birth and all these things, so, you know, I had a baby. But anyway ... but they can do, um, like a ... anyway, at [the cemetery] there's like a mass grave of babies. So they had a service and we went to that ... and like in a daze. Anyway, I don't even know how I drove in there, I mean, I don't even know how I did anything after that. But Derek, we went in together, I don't even remember talking to him or him even being there, I know he was, I know he was really supportive. It was like this huge, since then ... it seems to be this huge big veil gone over it all and that's why I've had this trouble remembering a lot of things that went on.

Whether or not it is practical or even possible to test gamete donors for genetic abnormalities is not the entire issue. Anna blames ART staff for what happened to her and believes that it was largely preventable. The lack of contact by ART clinic staff heightened Anna's perception of these health professionals as uncaring. If, however, these staff had acknowledged the difficulty of Anna's situation and been able to explain their position, that is their inability to test for all genetic abnormalities, Anna may have felt supported rather than abandoned. Anna felt greatly confronted some years later when she received a letter from the IVF clinic acknowledging that she was an ex-patient and asking for financial support. The fact that the IVF clinic had been able to make contact with Anna and her husband, even though they had since moved to another town, suggests that they may have been aware of the tragedy that had occurred.

Derek's story of this situation is primarily one of concern for his wife:

Derek (p. 7): Oh, it was hard, yeah, because ... a lot of the time it doesn't seem right because she's going through all this pain and stuff and time at the end of the road nothing happened, it was always a failure. Yeah, it was hard, because it's, you know, someone you love going through a lot of pain and distress. And it affects me too obviously and um ... but you know I felt very much part of it all

too, I think. Pretty much did everything, and ah ... I mean the worst part was that last bit. It was very distressing. And also when she was ... when we found out the baby was ... um, profoundly deformed and was ... probably never survive the birth and we just had to make a decision, we just couldn't bring a baby into the world like that, personally, so it was the right decision I felt. And but she still had to walk around pregnant with the bulge knowing that, because we had to wait a certain period or something to have it all done. And yeah that was the hard time, that week, it was about a week or two weeks after we found out and then we had to go to hospital and have it done. That was probably the hardest time, that really, that was definitely, that's it ...

In response to the question ‘Did that make up your mind to stop treatment?’

Derek replied:

Derek (p. 7): Yeah it's just not worth it if you have to go through all that and um ... support ... after that you'd think ... there wasn't much ... a lot of support from the medical side of it, after that it was like you were forgotten, which was disappointing. But ... you know, as long as we move on. It's not a nice thing to think about, that period.

Making the decision

Literature such as that by Pasch, Dunkel-Schetter, and Christensen (2002) suggests that having children is not as important for husbands as for their wives. However, the stories told by the husbands in the current research reveal more about men’s priorities. What is revealed throughout the men’s stories is that they reconcile with the cessation of ART earlier than their wives. The reasons for this are not simply because having children is not important to them, but a variety of understandable explanations relating to the safety of their spouses and a necessity to move on with their life.

Throughout participants’ conversations, stories varied somewhat regarding their feelings at the cessation of treatment. Emotions ranged from sadness to relief.

Sarah remembers the relief she felt at not having to actually make the decision to cease treatment herself:

Sarah (p. 2): But we kept on going, and then it got to the stage where you could only do it three times and then you had to do the tests again. And because I'd had so many operations the doctor said there's no way now that you could carry. The muscles, the lining, everything's just shot, you know, it's just had it. As you're getting older and older... because I was about between 38 and 39 then. And he just said, 'no it'd be a case where there's too much risk of losing you. So, yes you may have one but you're not going to be here to look after it.' And I mean that was a huge relief to me, because I would have been going until I was 70, you know, in the walking frame, you know, sort of going into to have the injections. Because there was no way I could have made that decision myself. So in that respect it made it quite easy for me.

Making the decision and realising what the decision actually meant were two very different things. Sarah expresses a sense of relief about not having to make the difficult decision about continuing or ceasing treatment, which is understandable due to the ambiguity of treatment. On the one hand ART provides hope for the much sought after biological child; however, on the other hand it exposes women to a series of physically invasive and sometimes life-threatening procedures, not to mention the negative impact it has on the psychological, social and financial aspects of their lives.

Rosemary recounts a very different story of discontentment of living with a decision that she was not entirely comfortable with. Control was a dominant issue not only in the decision to give up treatment but also throughout the ART process:

Rosemary (p. 3): So then we ... we went through a very difficult time, I think. James didn't want me to go through any more treatment. He said to me, I recall, We've spent ten of the twelve years of our marriage trying to get you pregnant and is this what we're going to do? And that seemed a maddeningly reasonable question. I ... and so for about probably twelve months ... Yeah, so anyway for

about 12 or 18 months I think, we sort of ... I was pretty much on automatic. I would go to work, I was depressed, I went to ... I had counselling, I was diagnosed with acute reactive depression and grief. I didn't have any medication, I just talked to people, but really withdrew. And ah ... I don't know how James and I got through that time, but we did. I had a friend in Paris who'd been very successful on IVF, twins on the first attempt and two years later on a second attempt triplets, who'd put back three embryos a second time. Um ... she offered me an egg and said that she knew a doctor in America of all things who would ... if she donated would go over there and do the procedure for nothing, I just have to get there. So I talked about that with James and he said to me, look I think in just telling you I didn't want to have any more treatment ... I mean it's difficult, having a baby, even when you're fertile requires some agreement, you know, so I understand that. I guess I thought that if I kept going, I'd eventually crack it. Because I had really good cycles, always had eggs fertilised. But I was in my late 30s by then. I don't think I was aware as what I am now of the implications of age. I knew that as you got older it was more difficult but I didn't realise I was really on the edge anyway at 38. So he said, look if you want to do this, then do it, but can we have some agreement about the number of times you want to ... you'll be prepared to do this. He said, 'I'll go to America with you, or you can go, we'll do that.' And it was interesting because for me, and I don't think I'm a control freak, not manically so, I don't know, but it made a difference. And I sat down and thought about it, and like two or three years had gone by, by this stage, and I was in my early 40s, so I knew that using my own eggs was pretty much a waste of time. So I thought about it and then I wrote her a letter and thanked her very much. It was just a wonderful gift to offer. And ... but I said to her, I think ... I thought I'd reached the stage where I wanted to survive infertility and that I didn't think I could put myself back through the not knowing that it would work. I knew it had a good chance of working because of her success rate and I knew that a lot of the success of donor egg cycles was dependent on the egg. And I had the best chance of it succeeding but I really wanted to ... yeah, that was all I could think of. I wanted to survive infertility and I'd begun in small ways to move on. So I thanked her very much but said no. And for me that was ... that brought a degree of resolution that I'd not had previously. I felt like I was more in control of the decision. And I freely acknowledge that it's not an individual decision to have a baby unless you want to have one with DI or something as a single woman. But that really helped I think, and it helped us. It also helped us as a couple because he was offering and even willing to pay for me to go to the States,

which I know to him would have seemed excessive. But it was the only way we could get the treatment. And that would have been cheaper than paying to go through it anywhere else. Yeah, so that was a good thing. I think that ... I think a pivotal time for me was when my baby had died. I don't think I'd been prepared for the impact that would have on me. My whole attitude to IVF changed at that moment. Even though I'd been very guarded about getting hopeful. I knew things could go wrong.

Participants' stories highlight the difficulties experienced whilst undergoing treatment for infertility, and convey that treatment-related tragedy or hardship was often the catalyst to ceasing such treatment. The stories also suggest that participants felt that had they known of the possibility of tragedies and hardships, they might have made different decisions regarding the procedures and processes they consented to.

Discussion

I acknowledge that it is not feasible to discuss all issues raised by the stories of participant couples in detail. Therefore the dominant underlying stories identified throughout this chapter will be explored under the subheadings of: shared hopes and expectations, technology: the solution or part of the problem, and ambiguities of success.

Shared hope and expectations

The very reason that couples access ART treatment initially is based on societal expectation that they become parents. The hope that technology will provide them with the much sought-after baby is evident in Greg's story where he says: '*There was always the hope that there would be this medical solution to the problem. And through that process (IVF process), I mean, the thing is we were encouraged, we did have feelings of hope that things would work.*' The definition of infertility

largely depicts the expectation of couples to be able to reproduce within a certain time frame. The definition mentions a mere twelve-month time frame allowable for a couple to conceive or carry a live baby to term. Societal expectations regarding ART outcomes have been fashioned by the media's portrayal of available technology, which accentuates positive outcomes, thus diminishing negative outcomes (Shanner & Nisker, 2001).

Societal expectation that ART will result in a 'miracle' in the form of a baby is illustrated in Rosemary's story regarding her first IVF cycle. She tells of her family anticipating a pregnancy, as this is how they had seen ART portrayed in a popular women's magazine. '*And my family was all preparing for quads, you know, as they've seen in the Woman's Weekly.*' With ART being represented in this light, the magnitude of the sense of failure at not achieving a pregnancy, even with the perceived miraculous assistance of ART, is insurmountable. Not only does the woman fail to conceive naturally, but she is unable to conceive even though she has access to the latest technology.

Addressing the concept of hope in this context Franklin (1997), describes the image of a desperate and infertile woman metaphorically signifying hope (for the miracle of a child) and faith in technology (to be able to provide this miracle) (p. 202-203). Franklin (1997) elaborates further, aligning this image with the unification of traditional family and faith in technology to improve the human condition (p. 203). The hope is thus not confined to the couple accessing ART but extends further to include "the shared collective hope invested in the promise of science and technology" (Franklin, 1997, p. 203). In light of the importance of ART in this context, it is not surprising that these couples were encouraged to continue treatment even when their chances for 'success' were minimal.

Participant couples struggled to fit in with the ideology of the normal family where that is defined as the nuclear family unit of a heterosexual couple and their biological children (Andersen, 1991, p. 235). Despite their efforts, they are living against the normative narrative. They have complied with the norm of society initially by getting married but then have failed in their duty to procreate. Although these couples are not able to live the normative narrative, they still strongly believe in the normative family ideology, making a huge financial and emotional investment in technology in an attempt to fit in. Throughout the treatment process, these couples often felt as if they were given false hope of a 'successful' outcome and therefore persevered longer than they otherwise would have. For example, Anna explains '*..but you **were** made to feel like it **was** going to happen. 'No matter what, we've done the best job here, we've done', you know ... and it was great that they had but in hindsight now I wish I was told then what my chances were, because as you ... as it goes on in the story, I mean, eight, nine years down the track, you know, they then start telling you ... your percentage chances of getting you pregnant, because they know that they're running out of time. But at that stage I was already quite low on time as well, you know, and I may have made other choices, if I had have known what was ahead of us and what the chances were.*' Also, as participant couples did not want to give up on the normative ideology of family, they may have continued treatment to prevent being an outsider, even to the detriment of their physical and psychological health, which is evident in most of their stories with the catalyst for treatment cessation being an essentially negative experience. The prolonged time these couples spent engaging with ART resulted in other life choices being unavailable to them.

Technology: the ‘solution’ or part of the problem?

Technology has been defined by Heidegger with the following two statements: technology is a means to an end, and technology is a human activity (Heidegger, 1977, p.288). So the technology associated with assisted reproduction can be considered as the means to an end, representing the technology that offers hope to infertile couples for the conception of a child, and as implied by Heidegger’s definition, utilising these means is a human activity. Heidegger’s impressions of modern technology are that it challenges and places unreasonable demands on nature, that it sets upon nature to gain maximum yield at minimum expense (p.296-297). To use Heidegger’s description as an analogy, the woman who undergoes IVF treatment is primed to ensure the maximum yield of oocytes, thus ensuring stimulated cycles are kept to a minimum, therefore being more cost effective. Although some would argue that a maximum yield of oocytes in fewer stimulated cycles equates to less invasive procedures, the unreasonable demands of such treatment can be quite harmful to the woman and more indirectly her partner both emotionally and physically. For example, Carl illustrates: *Um ... it was a very powerless thing ...for me to watch. Because all I could do was support and help her through it and help her through the pain and discomfort that was inflicted on her.* Ovarian hyperstimulation syndrome is just one of the complications caused by such a challenging treatment regime. As well as increased complications, the chance of gaining a ‘successful’ pregnancy decreases when embryos are frozen (Bryant et al., 2004).

Haraway (1997) differentiates between reproductive strategies chosen by various species, stating that traditionally human beings tend to have few offspring but make a larger investment in them, which in turn leads to offspring being

considered as valuable (p. 204). In contrast, species such as cockroaches and dandelions have as many offspring as possible, with very little investment in any individual, in the hope that some will survive and reproduce (Haraway, 1997, p. 204). With ART producing multiple embryos, and in light of the knowledge that very few are going to survive, this technoscience has the potential to remove the value placed on the individual embryo as a significant investment.

As well as the embryos being devalued, so were these couples who accessed treatment. For example, Anna tells of being ignored and thus devalued after her tragedy unfolded: *I never ever heard again from IVF, [the IVF doctor], from my nurse, nothing. And it still absolutely bothers me, from the point of view that they didn't even ... number one from the compassionate point of view, like to see how I was. You know, because I'm a patient. I thought I was, but I thought I was a person too.*

The lack of interest and caring by ART clinic staff perceived by participants in this current study may be in part explained by using Steinberg's (1990) argument that even the name 'IVF' depersonalises women by identifying the one step in a series of complex procedures that occurs outside the woman's body, that is, the fertilisation of oocytes in a Petri dish. With women remaining absent from the labels of assisted reproductive procedures, it stands to reason that treatment would have a technological focus with little room for the consideration and care of the couples undergoing these procedures. In reviewing the debate regarding nursing and technology, Sandelowski (1997) highlights opposing views of technological optimism and romanticism. As the name suggests, technological optimism embraces technology and proposes that technology facilitates not only the care delivered to patients but also the relationship between nurses and their medical

colleagues (Sandelowski, 1997). Contrary to this, and in keeping with the stories told by these couples undergoing ART, technological romanticism advocates for technology, depriving the nurse-patient relationship of the humanistic component necessary for holistic care (Sandelowski 1997); it puts the technology first.

The depersonalisation of couples is further compounded by the corporatisation of ART services. It is evident with the recent formation of conglomerates such as IVF Australia (IVFA) and Sydney IVF (SIVF) that ART services are not simply health services but are services primarily concerned with making profits. Robin Crawford, a director of IVFA, is quoted as saying the IVF business model is similar to “the fast food industry, with lots of outlets” (Saville, 2004). This ‘set menu’ of services depicts the limited services offered by ART and promotes the lack of individualised care afforded each individual who accesses this service. Greg highlighted the lack of individualised care as he talks about treatment received by Andrea remaining unchanged despite anatomical irregularities being identified in previous cycles. The statement by Greg that *‘every time was like the first time and they didn’t seem to learn from the previous occasion’*, exemplifies his knowledge that ART is a set procedural process that is implemented for all ART consumers regardless of their individual differences. Crawford also suggests that part of the reason IVF is such a profitable industry is that “most of the work is not done by the doctor, it’s done by the nurses and the scientists. You can leverage off that and add volume” (Saville, 2004). Sticking to stringent business plans in order to maintain and increase profit margins appears to leave little room for the holistic and individualised care necessary to deliver adequate nursing care. In spite of this, IVFA continues to advertise on their website that they provide all their patients ‘individualised care’ (IVFAustralia, 2005). The corporatisation of

ART services, however, signals a commitment to making money rather than to providing high standards of care.

Reproductive technology is promoted as a cure for infertility with the prompt referral to ART specialists at the first sign of a reproductive hitch, for example in Anna's story where she says: '*But she (doctor) just said to me given that fact and what it was that if we were trying to get pregnant she suggested that we should go and see an infertility specialist. Smack bang, straight away. Which we did. So I went to IVF.*'

Although the criteria for ART inclusion currently consists of the inability to conceive after 12 months of unprotected sex, some authors such as Brosens et al. (2004) advocate that investigations into female infertility should begin much earlier and propose that female infertility should be investigated after six months of fertility-oriented intercourse. Apart from the obvious absence of reference to investigating the much more easily diagnosed male fertility problems, the suggestion of earlier intervention further encourages technology to commonly become part of the conception process. This also suggests that earlier intervention makes for better outcomes, which is the belief system for all early interventions which may not be true, without discrimination of conception/pregnancy difficulties.

Ambiguities of 'success'

The word 'success' is problematic due to the multiple definitions, implications and varying discourses in which it is used. As illustrated by participants in this research, women often contribute to the 'successes' of ART but remain failures at reproduction. The very concept of the technology claiming 'success' in spite of its

many obvious flaws is somewhat puzzling. The asymmetrical way in which success and failure is apportioned means that women wear the failure of technology as well as the failure of reproduction, whilst ART wears all the successes. This is apparent in stories told by Rosemary, Sarah and Anna about their IVF miscarriages. Using a clinical pregnancy as a measure of success (i.e., evidence of pregnancy by clinical or ultrasound parameters, including ectopic pregnancy (Bryant et al., 2004)), their pregnancies would have been counted as ART successes even though the outcome of their pregnancies was by their own account negative. Anna recounts '*And then ... but he had done this thing where he'd cleaned out the tubes and he put that down obviously in his own records as being that was a success for him. So it wasn't a success for me, I can tell you, because I was pretty devastated.*' This extract shows how this woman carries the burden of the pregnancy failure while ART and the physician were 'successful' at achieving the pregnancy. Although ART fails to ensure the pregnancy is maintained to term and results in a healthy baby, each woman continued to see that they carried the burden of failure on technology's behalf.

Although Griesinger, Dafopoulos, Schultze-Mosgau, Felberbaum, and Diedrich (2004) point out that preterm birth can be as a result of many factors outside the control of ART programmes, providers of ART services remain willing to count any live birth as a success in order to promote their product. With success depending so heavily on the women, it is difficult to imagine how clinics can justify eliminating the women from the equation and promoting positive outcomes as 'successes' for technology. Griesinger et al. (2004) argue that apart from the medical profession needing to record various broader outcome measures, "gestational age at delivery does not seem appropriate to measure the professional

competence of a centre or programme”(p. 1241). Considering that the likelihood of survival is directly proportional to gestational age, (Draper, Manktelow, Field, & James, 1999) and in light of the fact that ART programmes currently claim all live births as successes, it is remiss of them not to take into account the number of complications and neonatal deaths as well, particularly in light of success rates being used to promote the status of the clinic (Griesinger et al., 2004). Apart from this, it seems that the information clinics are willing to share with their patients regarding outcomes remains limited. Outcomes relating specifically to types of infertility, age, and varying procedures may give couples a greater indication of what they consider their chances of success – that is of taking home a healthy baby.

ART clinic staff exhibit minimal concern regarding the health of their patients beyond conception and embryo transfer. They may follow up a ‘result’ in the form of ‘success’ or ‘failure’ but show neither concern for the women who have conceived, nor the health of the baby they are carrying. Wennerholm and Bergh (2004) agree with Griesinger et al. (2004) that the patient primarily influences preterm birth. Sociological factors, past obstetric history and complications of pregnancy are identified as being risk factors for preterm births (Griesinger et al., 2004; Wennerholm & Bergh, 2004). Whilst this shifting of blame serves to absolve IVF clinics from ‘failures’ of this kind, the reason(s) why the couple have presented for treatment need to be taken into account. There are many reasons why people access ART, only some of which include the inability to conceive, and in these cases successful conceptions may be reasonably counted as ART successes. However, if maintaining a pregnancy to term has been the primary reason for accessing ART, then a complication of pregnancy such as early labour,

and birth between 20 and 37 weeks gestation cannot be considered as a success but counted as an ART failure. Further to this, using the same technology and procedures to treat an inability to conceive and the failure to carry a baby to term is of questionable value.

Griesinger et al. (2004) claim that the purpose of ART is to overcome infertility, defining this as being an inability to conceive. Once this has been achieved and the patient is pregnant, Griesinger et al. (2004) state that an infertility specialist no longer sees the patient, and that therefore it may be inappropriate to use live birth as an outcome measure. This may be a valid point if the definition of infertility included only those who could not conceive. However, the widely recognised and accepted definition of infertility also includes those with the inability to carry a baby to term (FSA 2004), and the reason couples access ART is not simply to conceive a pregnancy but they also have an expectation that the result of treatment will be a healthy baby.

Despite the current debate regarding success rates, ART clinics remain divided on what should be determined as a numerator of success. Although some clinics agree that the safe delivery of a baby (or babies in the case of multiple births) at term is the ideal measure of success (Buckett & Tanner, 2004; Heijnen, Macklon, & Fauser, 2004), live birth per embryo transfer cycle commenced remains the most widely used measure of success in Australian and New Zealand reports (Bryant et al., 2004). The best measure of success according to Min, Breheny, MacLachlan, and Healy (2004) is the birth of a single live baby at gestation of 37 weeks or more as a result of a fresh, non-donor cycle in which ovulation drugs are administered. Whilst the birth of a single live baby at 37 weeks or more gestation is indisputably a success, the starting point of the measure consisting only of

fresh, non donor, stimulated cycles again falsely elevates what a couple would class as a success. Fresh, non-donor, stimulated cycles have significantly greater successes than frozen cycles (Bryant et al., 2004). To provide a more accurate indication of success rates all cycles (whether fresh or frozen, and donor or non-donor) require counting. Anna conveys the importance of accurate information related to chances of giving birth to a live baby when she says '*...and I may have made other choices if I had known what was ahead of us and what the chances were*'. The hope of a 'success' fed by ART services ensured participant couples' engagement with the technology, thus delaying decision-making regarding whether or not to continue to access ART.

Conclusion

ART clinics may serve their patients' best interests by focusing on individual cases, taking into account determining factors such as reasons for infertility and age, and giving realistic information regarding the likelihood of treatment resulting in a live baby that the couple takes home. Due to the falsely elevated and skewed 'success rates', couples often delay the necessary decision-making process regarding whether to persevere with ART, explore alternative methods of parenting or remain childless. As well as the ambiguity of the term 'success', the hope that technology brings often prolongs such decisions and at the same time may serve to compound the sense of failure experienced by couples.

The expectations of society that these couples would become parents did not disappear with the cessation of ART. Unlike couples who had fulfilled their reproductive role in society, these infertile childless couples were often expected to pursue parenthood in any way, shape or form that was available to them. The

following chapter consists of participants' stories regarding choices about alternative methods of parenting, and the impact remaining childless has on their lives.

Chapter Five

RECOGNITION / REALISATION

*The life we had is now gone
 Doctors, hospitals, procedures, drugs –
 Intrusions into your private life.
 Hopes, dreams.
 Disappointment after disappointment
 Month after month – year after year.
 All gone now – unsuccessful.
 But our lives took a different path.
 In a way, I'm glad it is over –
 Finished, finalised, time to get on.
 Sometimes it's all just too hard
 (Pamela Newman, 2001)*

Introduction

The previous chapter illustrated the importance these couples placed on the normative narrative of having a biological child. Following this, their stories were traced from when they first learned of their infertility, their paths through treatment for their infertility, and the adverse events that lead to their decisions to cease this treatment. Throughout this chapter participant couples tell of the feelings they experienced immediately following the cessation of treatment and the impact ceasing treatment had on their personal relationships with each other as well as with their family and friends. This current chapter conveys the next scene for participants in their realisation that they would not become biological parents, their decisions regarding parenting by other means such as adoption and surrogacy, and their experiences of remaining permanently childless.

In the absence of biological children, the expectation for these couples to pursue other methods of parenting had a fundamental presence in their personal relationships with others. This chapter will begin by illustrating the significance a woman's reproductive organs holds for some members of society. This serves to facilitate the reader's understanding of various reactions faced and highlighted by these childless couples.

The negatives of 'childlessness': its guilts and failures

Feelings of failure, inadequacy and general feelings of low self-esteem in relation to remaining childless often stemmed from the negative and devaluing views held by society in years gone by. Sarah's story illuminates how childless women were viewed when she was a child:

Sarah (p. 4): I suppose the ones that affect me most are my family, because my eldest sister is 20 years older than me. So therefore my mother was much older. She died probably eight years ago. And their views ... I mean, even while I was growing up it was always like, when someone had a hysterectomy ... she's barren she's useless. This is how it was in those days, how they view people like, and I grew up with that. And my sister at one stage was facing the prospect of having a hysterectomy and she was horrified because she thought, okay my life as a woman is over. It was that dramatic. It was really dramatic. And also like when I was growing up there was a couple that lived across the road from us that didn't have children and some of the ... I suppose, spiteful, horrible things that my mother said, you know, she's, like, bitter and twisted because she can't have children or she's a dried up old cow, something like that. That sort of always stuck in my mind and so that comes back to you as well, and you think I'm one of those people that they used to talk about.

Sarah's story resonates with information previously presented in the literature review (by Raymond, 1993; Wolf, 2001) that women's major motivation for striving to become mothers is to conform to social norms and social acceptance.

The importance Sarah's mother and sister placed on women's reproductive organs and capacities had a lasting impact on Sarah. These negative perceptions of childlessness were the basis of Sarah's perception of herself. After ceasing treatment for infertility and realising that she had no chance of having a biological child, Sarah's articulation of a sense of guilt and failure is understandable. She speaks of letting people down, not just herself and her husband but society as well:

Sarah (p. 2-3): I felt ... it was weird because I felt a failure and I find that very hard failing at anything, which is really bad. I felt incredibly guilty, still do, terribly, terribly, terribly guilty. And I mean subconsciously I tried to push Alex away, so he could go and marry someone, so they could have children. But it was very subconsciously, I wasn't conscious that I was doing it. And I think, even to this day, I think it would have been easier for me if he had gone. And so I wouldn't have to live with the guilt, the constant feeling of guilt. And that I've let him down, that I've let, you know, sort of, not only him but us down and life, society, everything, I just felt like a real failure. It's hard to explain but it's a real ... and it's constant, it never, ever goes away. It gets less and less but every now and again something will trigger it. Like if ... I mean kids adore him, absolutely adore him, they crawl all over him, like with my great niece she will cuddle up on his lap and fall asleep on his shoulder and he'll look at me you see the smile and it just kills me, you know, like ... something inside has died because of it. I don't feel like a whole ... Because you have to build such a strong core within you to cope, to keep going. And I think that wall, it's sort of a very solid wall, has made something die. Yeah, definitely, because you keep on going ... getting these things every now and again. I mean, I could be driving to work one day and it'll suddenly hit me and it's in my mind. You know, sort of, it would have been nice to have his little boy or little girl or something and you think, why, why didn't it ever happen? Well logically thinking, well it could have turned out to be a right little shit of a kid, I would have hated it. But in your mind it's always the perfect and most beautiful child that's going to be gorgeous. But then you never think logically at those sorts of times, you just get all guilty and feeling horrible and down and you sort of think, why? And that's all you do, you keep on saying, why? I don't know, there's no answer.

When infertility was solely attributed to female factor, women participants experienced feelings of guilt due to their inability to provide their spouse with a child. Like Sarah, the other participant women in this position subconsciously tended to push their husbands away in the hope that they would leave them. If this had happened, the women felt they would no longer need to feel guilty or blame themselves:

Anna (p. 21-22): You know, that it's me. That I'm the one ... he ... he was, you know, Mr Sperm King, basically, you know. And ... I still go through times when I think ... Recently I realised that a lot of the things that I do and say about him or do ... and react ... how I react to him now ... completely different than before all this. And I do that sometimes in a in an awful way to him, I treat him awful sometimes. Because it's almost like I'm trying to make him reject me. Because I ... I, you know, it's almost like it would be easier if he did at that and he went off and ... I've heard that before ... I never realised that ... I never realised that I thought perhaps I was doing that, but I have now come to the conclusion that I probably have done that since it all happened. I treated him, you know, afterwards, not the first couple of months but after that, really badly, you know, really ... like a fish wife, you know, I was just shocking. And also because again there is only the two of you and you are completely embedded in each others lives all the time, you don't have anything else to ... you know, have a dog, but you don't have anything else to worry about. You just become this person that ... that's completely, you know, he becomes your life. And then you think ... and the only reason why that is, is because all this happened and I'm the reject and I'm the one that couldn't do what was supposed to be done, you know, what we're all ... you know, thought ... what we were all conditioned to believe we should be able to do, and then it doesn't happen. And you know, I'm very lucky with the person that I'm with, very lucky. But ... you still just don't know really ... you just. I don't know what he thinks, I don't know if he ever sits there and thinks, I wish ... He sometimes watching a TV show and he's there, like a ... you know, that's a maternal thing that you think, you know, you see a show and there's a guy talking to his child or something and just ... and you see them and you think, oh my God you would have been a gorgeous father and all that. And I would have been an awful mother, you know ... I still, I think that, I think that. I

think now, I think that so that I make it easier on myself. But then I make it hard on myself by seeing him as an angel and thinking that he would have been a fantastic father and I stopped him from being that. Oh, all these things, which he just said I really ... I didn't marry you for that. I never married you, I never stood at the altar and said, all those things because I thought that in a years time we would have a baby or whatever. And he said, and so I always took it as what, would come would come. So he's really good. But that also makes me feel absolutely awful and guilty because he is so much like that. I don't know whether I would have been ... if ... if it had have been him that had the problem, it was always like it would have been better if we both had a problem.

Anna idealises the type of father her husband would have made whilst negating that she would have been an ideal mother. While Anna identifies such thoughts as a rationalisation for why she has been unable to reproduce, the intimation that she feels she is not worthy to be a parent emerges. Anna explains further that no amount of reassurance by her husband will ever totally convince her that he is and will remain truly happy sharing a childless life with her. Anna doubts herself as well as her relationship:

Anna (p. 24): You know I still wonder at different times, it's hard to communicate with, you know, and I think that's just the women and the men thing, but um, it's hard to kind of work out whether or not he would opt just for something different if he had an opportunity, that's what I often think. You know, if it was placed in front of you, you know, at the beginning, you know, here you've got an opportunity here with a girl, you know, that you love or whatever but you can't have children with her and here's one that, you know, you probably can love as well but you can have children. I just still wonder whether that's what a man would choose. I don't know, I don't know.

Even in the absence of female factor infertility, that is when male factor infertility was diagnosed as the couple's primary reason for their inability to conceive, participant women articulated they still experienced a sense of failure. This correlates with literature by Anleu (1993); Greil (1991); Greil, Leitko, and Porter

(1988) and Miall (1986) regarding courtesy stigmas and the way in which women class themselves as infertile even though the diagnosed reason for infertility is male factor. Aimee exemplifies this in her story:

Aimee (p. 11): Weirdly enough, I don't know if it's weirdly enough, but I've always looked at it as a couple thing, never as ... like even when we started, like even though the problem was with Carl I never looked at it as though it's his fault. Because we've always done everything together. Um ... that's just how we are. Um ... we've been together, what, nearly eleven years this year and that's how we've had our relationship right from the start, we do everything as a couple, basically. So there's never been any sort of blame. But one thing I did tend to do a lot, particularly after we started the IVF, I had a lot of self-blame. Because I thought, you know, the embryos are going into my body, it's my body that's failing us. And I had a lot of ... um ... a lot of guilt. Um ... yeah, after every IVF thing, I'd sort of feel very guilty and depressed and, oh it's my fault, it's my fault, sort of thing. Weirdly enough, when we had ... when I was diagnosed with the endometriosis I actually felt a little bit of relief, that there was something wrong. (laughs) Because I had something to say, oh ... Something to blame it on, yeah, within myself, so ... um ... I mean, the thing with Carl, we were doing the ICSI as well. So that, oh well that'll get around that, you know, they'll pick out the good ones, (sperm) so that's not an issue. But it always came back to me, it was my body that wasn't working, wasn't doing its part.

Rosemary also articulates a sense of dissatisfaction with her body for its failure to reproduce and elaborates about a sense of self-hate in the form of gaining weight after it was obvious that treatment was not going to provide her with a much wanted child:

Rosemary (p. 8): It's like I sort of viewed my ... it was like ... um ... when I was on treatment, I was convinced it was going to work at some stage, so I stayed really fit and everything ... but when treatment finished, it was like I really dropped my bundle in some way and I guess I viewed myself physically different, like my body hadn't worked, so I really couldn't have cared less. And so I've actually put on nearly ... um ... yeah four and a half stone, I can't think in terms of kilos. I've had

several attempts to lose it. I'm on about my 29th attempt and I've lost half a stone.

The idealisation of becoming or being a biological parent was common among these couples. The possibility of hardships associated with having and bringing up a child were never considered in depth, so the idea of having a child of their own was idealised as the ‘perfect life’, which made this loss so much more difficult to endure:

Andrea (p. 15): One of the things that probably makes me the saddest about this whole thing is how much I would have loved to meet Greg as a father and to experience with him the growth of his own ... being a father, that makes me very sad ... that makes me very sad. And I guess I had an expectation when I see him with kids ... gosh, you know ... it's just so sad.

The possibility of spouses being a less than perfect parent was not considered at these times when women in particular experienced a sense of failure due to their inability to procreate. This sense of failure extended beyond issues pertaining to reproduction, reaching all aspects of the women’s lives:

Rosemary (p. 5): So I was doing that, but on treatment I was just getting so tired I ended up pulling out (of university). So when I stopped treatment I went back to uni. And it was really interesting, I never failed a subject, but that semester ... just doing it part time, but that semester I pulled out of my exams after I'd done the preliminary ... I think we had to do an essay or something, there were other sort of elements of the assessment and it was, like the exam was like the last 20 percent. And I couldn't face it, and it was like, I just couldn't face any more failure, I just couldn't cope with that, so I withdrew and became afraid that I was just going to ... almost withdraw from life, like I wasn't ... I thought, I can't go through life not trying to achieve things, this is a bit scary. But I was really frightened by this and I really couldn't face it. And then I thought about it for a while and I was taking a three subject load and then I thought, well okay, I'll just do one, I can cope with one. But it took me six months to get up the courage to re-enrol to do that one subject. And when I got through it, um ... it was like, oh good, everything isn't going to go wrong all the time. I'd sort of developed, and I

still do have to some extent, this disaster mentality. If something's looking like it's difficult I'm bracing myself for total disaster. Um ... and I think it's a protective mechanism. So I did that and eventually I completed my degree and that was almost as good as a positive pregnancy test. When I graduated I just couldn't believe it.

Sarah describes similar feelings of fear surrounding failure and compensation she feels necessary for the fact that she has been unable to produce a child:

Sarah (p. 21): You need, because when you're a failure you've got to overachieve and be successful at what ever you do and that's where you get your esteem bolster from. Definitely. Because you've got to feel proud of something, if you haven't got a child to be proud of, you've got to have something that you can be proud of. So it's a compensating factor for sure. But it's not healthy, it's not a good way or the right way to live. And that concerns me and worries me, because I don't know what to do about it. Even though I'm there, I don't know, and I can recognise that it's wrong, I don't know how to break out of that or how to make it any different.

There was a sense throughout the women's stories that they had not achieved what many other women achieve in life, which is, giving birth to a baby. This was articulated by some as a type of deficit or failure, of letting other women down by not fulfilling this role:

Sarah (p. 3): So I find it very difficult. Where Alex's very social with his car club and his flying club. I'm always on the fringe, you know, sort of standing away. And I find it very hard to have close relationships, particularly with women, yeah, because I feel as if I've let the side down. Very much so. I mean, I have friends but I keep it very much at a hands off, not a chummy chummy type of person. I tend to grab Alex and make sure he's very close. I find it very very difficult to just go out there by myself. Very hard.

Sarah expresses the difficulty she has socialising without the support of her spouse. This not only emphasises the supportive role that her spouse plays, but the difficulty Sarah encounters in making and maintaining friendships because of her

sense of inadequacy. Further to this, Sarah isolates herself because of this ‘difference’ in her reproductive status, thus providing a further obstacle to creating and sustaining relationships with other women.

Living in different worlds

Initially friendships were lost during the time that these couples received treatment for their infertility. Participant couples perceive themselves, in hindsight, as ‘high maintenance’ during the time spent on treatment programmes. As ART demands an enormous investment in time, these couples were not always available to socialise with their friends. Also, throughout an IVF cycle, these couples were both stressed, and often not in the mood to socialise. In addition to this, participant women often had adverse effects from the hormone therapy they were receiving, including severe mood swings and a range of physical symptoms that made socialising almost impossible. Carl talks about how their friendships disintegrated whilst they were accessing treatment for their infertility:

Carl (p. 5): IVF did a really good job of hoeing through our friendships. Um ... to the point where we ended up with ... what started off as being the two strongest friendships we had are now quite distant. And anything else we had just fell apart, no one was really interested in ... I don't know whether it was a strength thing, or just the fatigue and they got sick of putting up with us or listening to us ... or they had kids and so they naturally drew further away from us.

After these couples had ceased ART, friendships were lost due to a lack of common ground and the necessity for different lifestyles. The difference in lifestyle between these childless couples, and couples with children is perceived to obstruct most social occasions. Sarah shares the impact her childlessness has had on one of her closest friendships:

Sarah (p. 15): And I mean we stayed... been friends for a while and then parted because it came to a stage where, and I mean I'm the Godmother of her children and everything and we were very close and she had a real problem when the kids were babies, she couldn't cope, so I'd sort of fill in and take care, and then when the kids got older and went to school it was like she never had any time because she was always running the kids around, and then she got into the mother's society with the school and the golf and I just didn't fit into that little box any more so we just drifted apart. No bad words or anything but she'd be going out with ... or having lunch with a mother, ... and she would exclude me. She said, 'oh I didn't ask you because we've all got children.' And I said, 'why?' 'Do you think I'd feel uncomfortable or something? I mean, yours are there.' And she goes, 'well you wouldn't have anything to talk about, because all we do is sit around and talk about the children or the school or that sort of thing, so I didn't want to put you in a position.' She was trying to save me from that environment but at the same time she was hurting me by not including me. So it's a really, really weird situation.

Apart from divergent lifestyles impacting on their friendship, Aimee illuminates further reasons for the social isolation often experienced by these couples:

Aimee (p. 4): That's really hard. Um ... another thing, we've ... um ... we've lost a lot of our friends, because ... through IVF and through not having kids. Because they've all, you know, they've all gone on, had their families, met other friends who have got kids ... um ... and quite often, you know, we won't go to sort of social occasions where there's too many kids around. Purely for self-preservation. Um ... yeah, so that's sort of, that's been really difficult.

Participant couples often perceived others as being insensitive to their situation due to a lack of understanding. Actions and comments perceived as insensitive were a regular occurrence in the day-to-day lives of participant couples, and in order to prevent the escalation of a negative situation these couples often chose to remain silent. Rosemary shares one such experience:

Rosemary (p. 12): Um ... but I can remember ... and a lot of churches on Mother's Day hand out little white flowers to women who come in. And I can recall going in there when I was in the middle of treatment and this young

woman, young mother, was handing out these little things. And when I walked in the door she went to hand it to me and pulled it back and said, 'no, no, this is only for mothers.' I mean, people just don't think, I mean you also learn to think, oh my goodness, you've got to be really ... you need to think before you open your mouth a lot. 'No, these are only for mothers.' And oh ... she'd have hit me, physically hit me, I couldn't have been more stunned. I didn't care about the flower, I couldn't have cared less, but it was again, you know, you haven't achievedJames was looking at me willing me not to say anything. So I've never been back to church on Mother's Day since, it was about ten years ago. And ah ... and I wanted to say to her, she had three children, I wanted to say to her, 'I've put ... excuse me but I am a mother, I just ... but my baby died.' Can you imagine socially ... this is ... my goodness, let me out of this room, this woman's gone crazy ... but my baby died. 'And in fact I think I've put more time and effort into trying to have the children I wanted than all your three combined, so don't talk to me about ... I'm not worthy to be handed a flower on Mother's Day', you know, it's so ... yeah. I just find it interesting to see how sometimes, and I'm not sort of paranoid about this, but sometimes how women with children are treated ... are sometimes treated differently to women without. Um, yeah, so I think there's a social context in which childlessness is viewed as not being quite complete as a woman. I don't see myself as incomplete not having had a child. It's something that I could have done, it's something that should have happened but it didn't. But I certainly don't see myself as ... yeah, somehow incomplete because I didn't have a child. I just view that as a, I guess an unfortunate life event. But um ... for some medical condition that hasn't been identified. Yeah, so ... I think there's ... what I hadn't been prepared for, I mean at different stages I was sort of not prepared for the impact of things. I guess what I hadn't been prepared for ... that ... is this ongoing social context within which I was viewing my infertility or my childlessness. And I tend to, as I said, I tend to sort of view it almost stepping ... looking from outside, because ... maybe that's a protective mechanism too but you sort of view it from the outside and think um, yeah you sort of view it somewhat wryly and think, isn't this interesting that this is ... ah ... yes, or if you were really busy doing something for your work or an interest that you have. Yes, these are never good excuses for not doing a multitude of other things. But if you're a mother and you can't because the children, blah, blah, blah, that's okay. But if it's anything other than children, that's not really a valid excuse. Yes, it's kind of curious, um, yeah kind of curious.

Rosemary's story once again signifies the ongoing nature of the problems associated with infertility and childlessness and the continual transition in moving on with their lives. Aimee talks about the need to maintain distance from friends with children as a way of self-preservation. The often painful reminders of their childlessness emphasised at social outings often proved too difficult for these couples. Aimee tells of the difficulty encountered when confronted with other people being pregnant and having children:

Aimee (p. 5): Because sometimes it just ... it becomes too much and I just can't deal with it and I just have to get out of that situation. Um ... like at the moment Carl's brother is due ... his wife is due to give birth any tick of the clock, and even now ... I can't even bear to think about that. That just gets me ... really angry, upset, totally irrational. I just sort of, oh. So that's one thing that does worry me a little bit, seeing them with their new baby and all that sort of thing. ... Yeah, I think I'm just avoiding it a lot. But, yeah, I just get very angry, very ... I feel very ... I get a bit depressed, it gets me depressed in a way ... very doubting of myself, I think, I sort of feel like I'm less than not quite ... complete, I think, yeah. It makes me question what I'm doing with my life, it makes me question everything basically.

Participants invested an enormous amount of their lives attempting to have a baby with ART, which sustained the hope of being able to live out the normative narrative. When years of treatment failed to produce their dream of a biological child, women who became pregnant and had children served as constant reminders of participant couples' failures. It could be said that the couples' focus on having children indicates a strong belief in 'family'. This increases participants' sense they were missing an 'essential' part of life. Not feeling complete was common for women and men who participated in this study. This is not surprising in light of the language that is used to label those who do not have

children. Words such as ‘childless’ and ‘barren’ denote a sense of being without something, an incompleteness of self.

Being misunderstood

Often these childless couples were the recipients of flippant remarks made by friends or acquaintances with children. Comments from parents regarding the negative aspects of parenting were not well received by participant couples who considered them to be unnecessary and unjustified complaints:

Andrea (p.18-19): And she said, ‘do you have children?’ and I said, ‘no I don’t’. And she looked at me, ‘oh okay’, she said, ‘look, if you’ve got any regrets you can have mine for the weekend’, or something like that, ‘and that will put you off for the rest’..... and okay, it’s irritating. But, I didn’t sort of ... let it out, I just think they are so narrow-minded, and they’re complaining about their lot. ... sometimes, yeah well, I’ll play,... I’d rather play chauffeur sometimes, if I had the choice of doing it over again, you know. It’s like ... it was more a feeling like there was a big split, a big hole, between people who have kids, how they look at us and how they are totally unable to understand. What did you want in the first place, why don’t you consider yourself blessed because you don’t and no idea of the kind of journey and the grief and pain that was involved. So it was more sort of a total lack of understanding, it was like me sitting on a different side of the world. Not everybody, some people understand. But often that was the feeling, of being totally misunderstood. And that sort of makes you pull back, it’s harder to share.

Participant couples conveyed their feeling that they would have willingly taken on any parental duty if they had their own children. However, for these couples, the thought of having to take over the care of someone else’s children, as suggested to Andrea in the story above, is not an inviting one. As these couples struggled in vain for many years to have children, parents who made flippant remarks regarding the negative aspects of parenting were judged as unappreciative of the fact that they had children. Although it is not unusual for parents to be judged

regarding their parenting skills, such criticism from these couples stems from an idealised perception of parenthood. After investing in the societal glorification of parenthood for many years, and undertaking invasive treatments that promised but could not deliver a positive outcome, the misconception that parenthood was an idyllic role is understandable.

These childless couples encounter multiple situations that encourage them to withdraw further from society in order to avoid comments and presumptions regarding what they were going through. The following story exemplifies a lack of understanding regarding these infertile childless couples:

Rosemary (p. 13-14): I mean another example of how people don't understand. I recall ... this was about six weeks after my miscarriage, so I was still feeling ... I was just still quite dazed. Um ... I went to a function with my mother and this young woman came up and spoke to me, she was oh in her mid 20s, and she said to me, oh look I was really sorry to hear about your miscarriage, she said, and I just wanted to come and say how sorry I was because I can sympathise with you, she said, I had a miscarriage last year. And she talked about how devastating it was and how you just don't think you're ever going to be happy again and all of that. And she said to me 'I know just how you feel.' And she was about eight months pregnant and she was holding a two year old by the hand. And I'm not ... I.... understand that I'm not suggesting that her miscarriage was any more or less devastating than mine, that's not an issue, but she certainly didn't have to face the additional issues that an infertile person faces, that if ... when you feel like you've really blown your only chance to have a child. If you've miscarried you've gotten this far and it hasn't worked then you just don't think you'll be able to ... you just think you're not going to have ... you really can't have too high expectations of being able to repeat it, not when it's taken nine years to conceive once. And here was someone who'd miscarried and fallen pregnant within two months. And I wanted to say, you've got no idea how I feel, we live in different worlds. But you can't say that again, because there's a lot suppressed. And you don't say it because it would have been unkind and unnecessary. But it was astonishing to me that she felt comfortable and thought she was actually being helpful by speaking to me when she was so ... at that time, seeing an eight

month pregnant woman standing in front of me was terribly confronting and with this two year old child as well. Um ... I was almost dazed in the conversation. And I guess again it just highlights how ... um ... being infertile is something which people generally don't understand.

Although the pregnant woman in this story may not have realised the difficulties Rosemary had becoming pregnant, this story highlights further difficulties that participant couples faced when they miscarried. These couples perceived that there was a lack of understanding related to how confronted involuntarily childless women may feel when faced with another woman's pregnancy and/or the proof of her 'success' in reproduction with the presence of a biological child. Although the loss of her baby was a recent tragedy and her grief still raw, Rosemary's story presents the common perception of participant couples that people who have children fail to understand them. Sarah tells of the difficulty in trying to explain to a close friend who could not understand that she was not going to be a parent:

*Sarah (p. 16): It hurt, ...and I tried to explain to her that everything **had** been done and she wouldn't accept it. She blamed me and she was very angry with me. And then, you know, she'd sort of go, 'but our children ... we're not going to have the children to grow up with any more.' And if I became upset because I'd I had a bad time or something, or get upset and cry or anything, well, 'why don't you go and see another doctor, and why don't you have test somewhere else or go to another hospital.' Or, I don't know, it was like she was, instead of supportive, getting angrier and angrier with me, it was really weird. But I think, looking back, I think it was sort of a selfish view as well, because she had this picture in her mind and it wasn't going to happen, so she got angry with me because it was my fault it wasn't going to happen.*

Sarah's story illustrates the stake that others have in a couple's ability to reproduce. Sarah's friend seemed more concerned with her own loss of an ideal life than being supportive to a friend. In a way this is insightful, recognising that

there is a difference between those who have children and those who are childless, and provides a view of how these two groups grow apart. Friends may simply want the childless couple to play a large role in their life and believe that without children they will inevitably take different paths in life.

Don't give up!

It was often more difficult for other people to accept that participant couples had ceased treatment for their infertility and were going to remain childless than it was for the couples themselves. Those who persisted in insisting these couples become parents by any means available were considered insensitive and unsupportive. In particular, Aimee and Carl had difficulty with an infertility counsellor when they discussed their decision to cease treatment and move on with their lives:

Aimee (p. 1): We'd made the decision and we went in to go and discuss it with her (the counsellor) ... well basically tell her that we were happy with what we'd done (decided to cease treatment). We went in and told her, and she was really ... we got the impression from her that she thought we were making the wrong decision. Which was a shock because in the whole time that we'd spoken to her she'd always been really supportive of us and very ... um ... oh, sometimes she'd play sort of devil's advocate and give you different ways of looking at things, but we'd always come to our own decision and she was very ... um ... questioning a lot of things that we were saying. And we just got ... we both felt very uncomfortable and got this impression that ... um ... just that she thought we weren't thinking it through and that we weren't ready.

This story raises concerns regarding the ethical issues involved with ART clinics providing counselling for those who access this service. High among concerns is the possibility of a conflict of interest between what is best for the patient (i.e., the couple) or best for the business (the ART clinic that pays the counsellor's wages). A counsellor's role is intended to focus on what is best for the patient. In cases

where participant couples took the initiative to move on with their lives rather than pursue further ART, it is reasonable to expect such decisions be encouraged and accepted. ART counsellors may question couples to determine if decisions regarding the cessation of treatment are reactionary, as a result of repeated disappointment. However, Carl and Aimee perceived that as their counsellor was intimate with the impact that ART had on them socially and personally, she should have known their decision was not arrived at impulsively.

Counsellors employed by ART clinics were not the only people to discourage these couples from ceasing treatment. The idea that a couple will not ‘achieve’ a pregnancy and even with such amazing technology will ‘fail’ at reproducing a biological child was also a difficult concept for people not associated with treatment. Aimee recounts a common reaction she faced after making a decision to cease ART:

Aimee (p. 19): But you still get people sort of almost ... um ... I don't know if they're trying to make you feel better by saying, 'oh but there's other things you can do, don't give up', you know. It's like we're more comfortable with the idea of giving up than they are. And ... yeah ... I find that really strange. (laughs) I wasn't expecting that at all, actually, when, you know, after we sort of stopped and then we were telling people and we were getting this sort of weird attitude back.

Carrying a heavier load

The perception that childless couples were expected to carry a heavier load was common throughout participants’ transcripts. James elaborates on the expectation of him to take on extra work:

James (p. 8): And that's probably it ... that's probably another thing where it still does impact, and that is where work colleagues will make an assumption that you can devote more time to your work because you haven't got children. So it's all

right for you to be doing ... doing extra, because you know, (they say) 'well I've got to go home to two children, so ... but you can, you can carry the load because well you haven't got kids,' so ...

Rosemary story further indicates this expectation is not confined to work but is common in their social lives also:

Rosemary (p. 12): And even in social settings where ... sometimes assumptions are made, for example, if you're involved in a club or somewhere else, they'll be saying, 'oh so and so's too busy to do this because she's got to get children off to school, oh Rosemary will you do it?' Like being a mother is the only reason you could possibly be busy in life. And I now sort of choose to be mildly amused by that and just say, look I'm sorry I don't have time. Or if I do, I'll do it. But there's this sort of excuse, motherhood is a wonderful excuse for all sorts of things.

The belief that there are fewer demands on childless couples' time may explain this mindset. This assumption further devalues these childless couples, implying that their lives are less important than those who are parents. Further to this, organisations have initiated family-friendly policies that assist people with young children. For example, the implementation of such leave entitlements as parental leave clearly favours people with children.

Parenthood? Or not?

Prior to enquiring into why participant couples did not pursue 'unconventional' ways of becoming a parent, it is helpful to understand what being a biological parent meant to them. Carl's story presents his impression of being a biological father:

Carl (p. 8-9): ... the initial part is naturally the pregnancy, being part of that nine month process with Aimee and going through it with her and then the birth, being there. Having the child. Then there's the hell stage, when you go home for that first six to 12 months and your life gets turned upside down and you're looking

after this completely helpless being that relies solely, totally on you for everything without fail. Working through that as a couple and having that being part of our lives. And then once they start to become an interactive human being, I suppose, for want of a better word, where you can actually start to teach and make them part of your life and watch them develop and mould them, I suppose, into the product of both of you. The genetic part's already done and now it's the, I suppose, the psychosocial part of producing this little human being. And watching the achievements of the child and yourself, okay, and taking pleasure in that. Watching their failures, and helping them through it. And berating yourself for ... what could I have done that would have made that work better, and that sort of thing. Yeah, I suppose, up until adulthood and the challenges and the ... the prizes that go along with that, the enjoyable parts of what ... that was my perception of being a father anyway. And it still hurts me that it won't ever happen.

Adoption was suggested to these couples as if it were a revelation, being presented as though this ‘solution’ to their childlessness was something that had not been previously considered. The method of ‘acquiring’ a child by adoption was discussed as though it was a natural progression for these couples. Mann (1999) revealed that this attitude was common in the 1970s. In the past 30 years, societal attitudes have not changed significantly regarding the presence of a child in the home of a married couple as denoting a family unit. There have been significant changes, however, in the number of children available for adoption in Australia, and also major changes to legislation surrounding adoption. It would be naïve to suggest that these couples had never considered adoption, but for many reasons, this ‘solution’ to their childlessness was perceived as problematic. Therefore these couples remained permanently childless (and here I must point out that I have avoided using the phrase ‘chosen’ or ‘made a decision to’ remain childless, as some couples did not believe that they had such a choice as their age on the cessation of treatment excluded them from adopting a child).

Due to a variety of factors, including greater societal acceptance of single parenting and financial support available to single parents, there are increasingly limited numbers of healthy children available for adoption in Australia, and even fewer newborns. Carl articulates further concerns experienced by participant couples when faced with the prospect of adopting a child today, particularly concerning autonomy in the decision making required when raising a child:

Carl (p. 3): Um ... starting off with local adoption and that was a very, very brief investigation. Because there's no such thing any more in [this state]. It's now called permanent care ... um ... and it means that the birth parents have got access and rights and they've got a say in how the child's raised. So what they do is they get away with it scott free financially, we pay for everything and at the end of the day they're the ones making all the decisions. So I just went, oh that's bullshit, I'm not going to ... I'm not free thinking enough to have someone who doesn't want their child to then step in and tell me how to raise it. And not all of them are ... there are some people out there who genuinely can't keep their kids and if they were to have input that would be fine, because they're probably never going to be able to take their kids back anyway. (p. 4) A lot of the other places, um, had religious connotations in their requirements, you had to be a Catholic or a good Christian family or whatever. Um ... and whilst we are spiritual in a way, we're not openly, actively, religious, um, we have our beliefs. And our beliefs wouldn't have fit in with what they want.

Pointing out these issues expressed by the participants of this study in no way intends to devalue any person or relationship between adoptive children or parents. However, the presumption that adoption is a substitute for those who cannot have their own biological children is obviously seen as problematic by participants in this research. Adoption has always been a very different process to conceiving a child of your own, and with current legislation that continues to recognise some rights of birth parents, some couples are no doubt deterred. This legislation was put in place to protect the adopted child as well as their biological

parents and in theory works for the benefit of all concerned. However, the added restrictions and demands on potential adoptive parents, as well as the knowledge that there are so few babies available for adoption, deterred participant couples from pursuing this option.

Apart from the adoption of a child being a very different way of becoming a parent, it carries with it a multitude of complex issues that need to be considered prior to initiating the adoption process. Participant couples shared the view that to adopt a child was also a stressful process and was something that they could not face after the rigours of ART. Carl articulates a sense of relief at the decision made by both he and his wife not to adopt a child and voices some of his concerns related to the adoption process after ceasing IVF:

Carl (p. 4-5): It was actually a big relief, a big weight off the shoulders. Because we were going to go from one form of hell to another. From the IVF treatments to adoption, which is just as stressful. And ... because they put you through the wringer. All these countries do, and locally as well. First DHS (Department of Human Services) have a go at you, and goes through you like a dose of salts and then they hand you over to the other country who normally aren't quite as warm and fuzzy as the western societies are. So when they go through you, they really go through you. And we've had issues with my family and that sort of thing ... um ... and we had to think about what sort of support network we've got down here. We've got my sister who's down here but she's probably less than reliable ... ah ... and, apart from that, we don't have a lot of support network. IVF did a really good job of hoeing through our friendships.

Although overseas adoption is increasingly popular due to larger numbers of available infants and the reduced likelihood of having to 'share' the child with their biological parents, for the couples in this study, different concerns were raised. Overseas adoption comes at significant financial cost to the adoptive parents and, after the financial cost of ART, is unaffordable for some. Apart from

the financial cost involved in adoption, there are emotional considerations to consider also. Aimee shares her thoughts on pursuing adoption after ceasing ART treatment:

Aimee (p. 6): We actually went to an intercountry adoption information night and came away saying, yeah, we're going to go ahead and do that. Um ... we got very ... I think we got that renewed sort of excitement thinking, oh yeah we'll end up with a child this way, you know, for sure. Then we ... I think reality hit and we started thinking about it and thinking how that's, you know, giving up IVF that was, we were okay with that, but starting this whole other ... um ... I guess, form of treatment, whatever, which could take years and was going to be just as intrusive on our life as IVF has been. Not to mention the cost of it all, you know, thousands and thousands, which we didn't have. Um ... we started thinking, do we really want to do that ... um ... you know, put our lives on hold for another so many years. Like, cause we put out lives on hold pretty much with the IVF, and um for all those years. And we sort of started thinking, no I don't think it's worth it any more. We're not willing to give up anything else for it, we've given up too much and ... um ... yeah, we sort of decided against it.

The reluctance to pursue adoption did not denote participant couples' aversion to parent an adopted child, but signifies an unwillingness by these couples to embark on further intrusive processes without the guarantee of successful adoption. James illuminated further considerations regarding overseas adoption, raising not only issues regarding his eligibility and suitability for parenting, but highlighting the point that adopting a child from another country may challenge individual and familial ideals:

James (p. 4): I just think the concept of going overseas and getting a child, I mean, at that stage I hadn't travelled very much either, so it all seemed a bit ... it all seemed a bit foreign or unusual to sort of think that that was what we need to go through. And the bureaucracy was pretty heavy from what ... as we started to get into it, in terms of what their expectations were. And then there was sort of implied in the process were judgements about whether or not we were going to be a good parent. And so I was sort of reeling a little bit at that. Then I think it

was ... I mean there was sort of racial question that we looked at getting a Sri Lankan child at one stage and so sort of ... I don't know that I was ... um ... you try not to think that you're racial in your views but the thought of having a ... and there didn't seem to be an issue at all for Rosemary, nobody was worried about where Mum and Dad would be coming from, the parent sort of perspective on things. I think about it now, I think there'd be a lot of issues still to work through but I feel more comfortable about that ... that's not the option. And then there was age things and that too coming through, so that was ... I think there were age problems with my wife... being older than me.

For these childless couples there seemed no justice in this process. Initially they are devalued for not having children, but if they pursue adoption they must endure judgements regarding their parenting suitability. Although understanding that this process aims to protect the child, once again their worthiness as parents is in question. As well as others doubting their parenting capabilities, some participants doubted their own ability to love a child that was not their own:

Andrea (p. 24): Something that really struck with me is that we knew someone who'd adopted three international children...and the way ... I remember being so shocked the way she was talking about her kids. How she was seeing all those traits that had nothing to do with her and how dare her kids carry on like that, she'd done everything. Well as a result one of them committed suicide on top of that. But I was thinking, my God, if I ever ... you know how I can see when couples have a child and then they separate and they get to hate each other and then one of the partners might be looking at the child and see everything that they really despise. And for me I was worried that what if I ever look at this child and think, gosh Chinese, ugh ... I'm exaggerating but I'm seeing something that I despise. And I know every parent must to a certain degree even must be thinking the kids ... but I don't think I could live with the guilt of making a decision and yet not loving (an adopted child). I think, I don't I think, I don't know, I just felt like it's such a huge risk to take. I couldn't really take it. And yet I entertained the idea many times. And then that helped me in the fact that he (husband) was reluctant because it was only reinforcing a little bit what I felt. It was very much about my fear of not being able to love properly and make a child suffer. ...So, that was never really on the cards.

Participants considered the concept of becoming a parent by other means such as surrogacy or donor gametes a very different prospect. The idea of having children encompassed more than the presence of a child in their family, it represented a shared love and the continuance of that love and commitment to each other. Greg further explains the significance that creating a biological child holds for him:

Greg (p. 18): I mean two totally discriminate individuals and this is what's always been amazing, who can come together and create something which is in fact uniquely their own, that's one thing, and everything that goes with it, you know personality, being involved in that child looking after itself, getting something back from that, giving ... you know, I mean it's very hard to articulate this in a general sense, you know, sort of being part of you.

Therefore, like adoption, conception using donor gametes was perceived to be a different prospect to conceiving a biological child, even though using a donor can be done discretely so that the biological origins of such a child would not be questioned. Andrea shares her thoughts on why alternatives such as donor gametes were considered but not pursued:

Andrea (p. 24-25): Greg I think said that he would agree if I had a child with a sperm donor, or something like that. But I wouldn't even entertain the thought for a second, I mean, it just ... If I was going to have a child it was going to be our child, or possibly a child that we adopted together. But if it was going to be a biological thing, it was going to be both of us or nothing. It just didn't make any sense to me. I didn't have a craving for a child, so much that any body else's child would do.

This way of thinking may well stem from the argument put forward by Wynn (2002) that bonding between mother and infant begins long before birth, and puts paid to the view that the presence of an adopted child replaces a biological child. Adoption has many different issues for the participants and is not regarded as a substitute once considered beyond what is social expectation. For these couples,

going through pregnancy was seen as an integral element of becoming a parent, therefore further discounting adoption as a potential parenting option. Aimee shares the importance pregnancy holds for her:

Aimee (p. 25-26): ...the weird thing is, sometimes I think about, you know, having kids and what a hard job it is. And I sort of think, sometimes I don't know if I really want that hard job. But I would always have liked to have that experience of pregnancy and I think being a complete woman. (laughs) Which sounds like a bit of a stupid statement, but that ... um ... I think I'll always maybe feel that little bit less because I haven't gone through that, and because it's always expected that every woman will do that. And ... which is, I guess, that whole motherhood expectation thing, you know, with society, you know, women get pregnant. Women are the ones who are going to, you know, create the population of the future and stuff. Um ... I think, yeah, I had this picture of ... um ... yeah, I've always wanted to experience pregnancy and I've never, never done that. To have Carl's child, to perpetuate his line, I guess, you know. To have something that's a combination of us, I guess. Um ... I used to think about it a lot, now I sort of don't, I try not to. When we first started, um, I mean these yearning feelings were really, really, really overwhelming. It was almost like a physical ... um ... craving (laughs), I don't know. Um, I haven't had that for a long, long time. I hope they don't start any time (laughs) soon either. But they were very ... um ... it was like I just had to have ... had to be pregnant. I had to be pregnant there and then. Now it's more ... I think the yearning I have now is more of ... um ... um ... it's not as strong, I mean, I still occasionally sort of think, oh I wish we had a baby, I wish we had our own child. But it's no where near as bad as it used to be, so yeah .

Aimee speaks of yearning for a pregnancy conceived by her and her husband, describing this feeling as almost a physical craving. The importance of experiencing a successful pregnancy is evident in her story and surpasses the need for simply any parenting experience. Aimee describes what was commonly dominant in women's stories regarding feelings of incompleteness or emptiness due to their inability to carry out this function that is perceived as an integral responsibility of women.

However, Anna highlights not just the importance of the experience of pregnancy but reinforces the significance of having a biological child when she discusses reservations she had prior to accepting a donor oocyte from Beth, a first degree relative:

Anna (p. 6-7): It was, it was pretty hard, because, you know, it's almost like you're feeling like, you know, um, you're just not good enough, there was that. And then also the other thing was that, you know, you're still thinking it's not really going to be mine to begin with. Um, I felt ... I felt happy that it was, you know, still kind of family genes, which is the way that they want you to think. You know, and you have these interviews where they go right through all that with you. And, funny enough, they say all those things to you and they have an interview ... um ... I don't think anything is going to really be honest in those interviews, you know, because ... whilst I say that now about ... you know, it made me feel like inadequate and all that ... I didn't say that in that interview, because I'm not a dope. I know that if I say anything that's going to make me seem like I'm a nutter or you know, it's going to jeopardise treatment... and you know that's the thing... Beth, of course it didn't bother her because she wanted to help me and she knew that that's what I wanted. So, I mean, she interviewed fine. Derek had some reservations and they said to us at the end, you know, it ... that was the thing, he had a few little reservations about it. But he, again, did the interview the right way, I suppose. And so, you know, we do that and I think that ... and I think that, you know, obviously you can't stop somebody from not saying, you know from ... they're going to say the right thing unless you're really stupid. So they do this interview process and yes, you're okay. I don't know what it is you have to say, what someone would say to make them say no, you know.

Outside the traditional family

Parental disappointment

James talks about the impact that his childlessness has on the relationship with his parents:

James (p. 5): But I think there were expectations from them (his parents) that there'd be grandchildren. And there's only my brother and myself and he had ...

he separated from his wife, so they initially had sort of a fair amount of contact with my niece ... this was early days, but since then they ... I don't think they have much contact because his ... he has a new partner, a new lady, and they've been together probably, I don't know, eight or ten years or something. But I think there was an expectation from them that they'd be grandchildren around. I don't know how strong it was. I mean, Mum used to say things like, 'oh well what you never really had you don't really ever miss.' But I have also mentioned to this other family, sort of very ... had a lot of grandchildren and the like and ... So while there was an expectation I don't think they're totally ... they never conveyed to me any great disappointment to me. I think Rosemary felt as though she'd sensed it. And they were initially living out this way and then sort of moved away. I think there were lots of reasons for that though. So ... um ... I think it probably would have added another dimension to the relationship between my parents and myself. It's not something I've really dwelled on a lot, I try not to ... well, I say try not to ... I wouldn't ... there's never been ... never seemed as though there's been a great deal of value in exploring that when it's ... because it seemed a little bit futile.

When referring to children perhaps adding a whole new dimension to the relationship, James alludes to an absence of feeling, discussion, or perhaps even an element of enhanced respect from his parents if he had been able to produce grandchildren for them. James attributes these perceptions to his own feeling of disappointment with the fact that he has not provided them with grandchildren and not as a result of anything his parents had said:

James (p. 5): I think I've felt for them. I think that's affected my relationship with them to that extent because you're conscious of the fact that they've, you know, they've not had the enjoyment they would have had, had we had children. Yeah I think I probably would have liked to have pleased them in that sense of knowing that if I had children the joy that would have brought them. But I've not felt from them great disappointment or anything. I mean, they've said as much that it hasn't been. So whether or not they were just saying that in order to ... so that I didn't feel that.

Contrary to James' experience with his parents, other participants clearly felt the disappointment experienced by their parents at them remaining childless. For some participants the issue of continuance was so important to their families that they were disinherited, as they had no children to pass on heirlooms. For the participants that were disinherited a range of emotions were evident:

Sarah (p. 18): The thing that did hurt was like the jewellery, my grandmother's and my mother's didn't come to me, because they were to be passed on to the grand-daughters. And that ... I got absolutely nothing, absolutely not a thing. And I sort of thought, well it would have been nice to have ... I didn't want something that was worth thousands of dollars, I just wanted something that was personal of my mother's. And I felt very angry about that, and very bitter.

Rosemary tells a similar story of being disinherited as she was the only sibling not to have produced children:

Rosemary (p. 7): And then in my own family, after my father died with the reorganisation of my mother's assets. She eventually came to me and thanked me very much for all the help I'd been for 18 months and said I was wonderful and she thought I was strong ... I knew something was coming then. And she admired me and everything else, and she hoped I would understand but she was going to leave everything to my brother and sister who had children because she wanted to maintain contact with the grandchildren. And she felt that would be at risk if she shared it equally amongst her children is an interesting thing to consider. Um ... anyway that led me to ... that was very ... we're not rich, so fortunately it wasn't a devastating blow in that sense, financially. But ah ... it was, I couldn't really understand it and it ... it was quite shattering in the way that it ... I found it shattering in the way the decision had been made. And I also knew from the conversation we had that I was expected to take this and not to rock the boat and to be happy families with everyone forever and a day. My brother and sister were noticeably silent throughout all this process, no doubt not wanting to give up the additional funds that were coming their way ... and I decided in the end, it was so hurtful, I didn't think I could continue to see them all the time and for this not to have an effect, which may mean that I was being petty or something. It was more than that to me, because I'm not a petty person. And I thought, this is going to

poison me and I have to take ... I felt like my sort of sense of dignity had ... someone was trying to take it from me and that by saying this was okay, I was agreeing with this, that I was somehow to be valued differently because I didn't have children. And I didn't believe that I was any less value as a human being because I didn't have children, I didn't see that that should be attached to any perception of who I was.

Perpetuating a name

The importance of biological parenthood to men who participated in this study included a sense of continuance, which manifested itself in the form of continuing the family line, or more specifically the family name:

Carl (p. 9): And it still hurts me that it won't ever happen (biological parenthood). Um ... the last time it actually hit me would have been a week ago, a bit over a week ago. I was paying my fees at University ... um ... and the woman there, said, 'wow,[surname] that's an unusual name'. And the first thought that came into my head is, 'yeah and I won't ever perpetuate it'. Um ... that really hurt, it really did. Um ... and that does happen, that still happens, you know, someone will say something ... and ... and the thought that'll come into my head will be so irrelevant to what the discussion's about. Um ... and I accept that as something which will be with me for the rest of my life.

The sadness expressed in these stories highlights the importance men place on having a biological child. Derek also discusses how he would have liked a child to carry on part of himself, as well as the importance of carrying on the family name:

Derek (p. 8): Um, but yeah, when we got married I always thought it was always possible and always would like to have met had part of me in the world to live on. Yeah, and ah ... whereas it's stopped, which is sort of sad in a way and I felt sort of ... sort of sad for my father, like it stops here. Although my brother's continued, which is ... thank God for that. That's gone that way, that's all right. But, ah, yeah ... sometimes I felt for my father ... a little bit sad that maybe he'd miss out on the grandchild, which continues his ... you know, genes ... So ... as I said, thank God my brother's got a few children now and then his ... also his son's had a child too, so ... so that's good.

Watching other people and listening to them talk about their children is something that can prove extremely difficult for these childless couples. Feelings of envy are common, as are judgments as to whether the parents are deserving of their children. Carl talks about the expectation on him to father a child, the reality that he will not, and the resultant difficulty he has communicating with those who are parents:

Carl (p. 11): Yeah, it does to a point for me, because there was always so much ... and it was, you know, it was the old patriarchal ... must be a dad type Australian Anglo attitude, not even just Australian, it's a real, just about every culture in the world expects every man to be a father and every woman to be a mother. I guess the only question about procreation is the point of us all being here. And so that ... it's always going to be there, because it was ingrained into me from such a young age. Um ... and so that clash of the fact that whenever someone else starts talking about their kids and what they do with them as a father, and that sort of thing, it sort of ... you know, gives me that sort of ... somewhere between envy and hatred. Um ... depending on the person, there are some people I can look at and just envy them, because I know they're nice people, and there are some people I can look at say, you dickhead, you just don't know what you've got, you just don't appreciate and you don't deserve it. Um ... and it's not just clients I'm talking about, it's work mates as well. They just seem to think that children are an embuggerance¹⁶. Um ... and ... so that still happens, I still get that, that little pang of envy. Um .. and sadness, it's ... that I know I'll never be that.

Carl refers to '*procreation is the point of us all being here*', thereby highlighting the sense of worthlessness he felt due to remaining childless.

¹⁶ Military slang, meaning an impediment or an encumbrance.

Growing older

Growing older without children was a major concern for participant couples.

Being alone in old age and having no one to care for them rated highly in their stories:

Derek (p. 2): And as I said, the only thing that probably concerns me, but I don't think about it too much, is when you're much older. It's like my father, he's 93 or 94 now and we look after him now. Although he's quite fit and healthy, but he'll have nothing to worry about because I'm around, my brother's around. When we're 90 or we reach that age, there's probably going to be no one around, that's the only thing. So we've got to look after ourselves, we've got to make sure we're in that position where we can look after ourselves financially or whatever, you know.

Sarah (p. 18): Yeah, I mean, I keep on saying to my sister, you know you're really lucky because you've got the kids to look after you. I'm not going to have anyone to look after me. So old age ... I'm paranoid about old age. I have got to ensure that I have enough money to support myself and be comfortable. I am so scared of being alone and not being able to support myself. So my entire goal in life now is to have sufficient money to make sure that I can support myself without any help. So that's another strange thing. It's a real obsession, absolute obsession. I panic, which is not ... and then I ... said to my husband knowing my luck, sort of, I'll get to the age of retirement and get run over by a bus. He said, 'well I'll have a good time.' Oh, dear. And I said, 'well just in case it doesn't I'm going to make sure that I'll have sufficient to be independent.'

The fear of being alone in old age is a realistic one in light of research by Rowland (1998) who found that the likelihood of institutionalisation considerably increases in women who remain childless. Further concerns expressed by participant couples relating to childlessness in their older age included the perception that they had no children to inherit what they had collected over the years. Sarah shares her dilemma at the thought of not being able to pass on items she considered valuable:

Sarah (p. 17-18): And I went through a really bad time at one stage, because I said to my husband, like he'd buy me jewellery or something and it would really upset me and I'd cry. And he'd go, 'why?' And I go, 'I haven't got anyone to leave it to.' And I wouldn't sort of buy anything nice for the house, or anything, because I'd sort of think, what's the point? And he sort of went, 'God you're weird, stupid woman.' He goes, 'Because you can enjoy them,.. when you're dead, who gives a stuff? What happens to them, where they go, it doesn't matter, you're not here, you're dead.' And so I had to change my way of thinking, because I was always thinking, well, what's the point if I haven't got someone to leave them to. And he said, 'You can be enjoying them now, just you, because you want to.' And I went, oh okay. That was really weird, that was strange.

Andrea's story is closely aligned with Sarah's regarding concerns that heirlooms she has inherited and/or collected will never be passed down to her direct descendants:

Andrea (p. 10): But there are issues about ... yeah there's issues of sadness, there's issues like you know looking at all the stuff my father sent me, over the last three years he's done an amazing amount of work about the family history and that always makes me sad because I'm thinking, it's not that it finishes there but I'm thinking all these things that he's actually prepared for me, I can't pass it on, you know. And there's things like when you do your removal and things like that and you pick up little things and particularly in your life, sitting on the desk over there is the ink thing, the glass thing, it is my great-grandfather's, who used to be a teacher. And this has a lot of value for me and it's sad to think that this is it. But ... yeah, I've got a niece but it's not the same thing. There are issues like that but they're not, they're not tearing me apart, you know. They're just sad things, that's all.

The sadness experienced by participant couples is due to the reminder that they will not become parents. With this reminder comes the realisation that they will not share the traditions of their ancestors by passing down selected items to their offspring. Sadness due to the inability to hand down heirlooms to future generations may also be felt by parents of childless couples, thus providing a reason why some participant couples were disinherited by their parents.

Discussion

The realisation by participant couples that they will not become parents denotes a different story of life from the norm, a counter-narrative from the common one of marriage followed by children. The following discussion addresses the major concepts underlying the realisation chapter including, the distinction between biological and other forms of parenting, guilt and failure, and societal values and isolation.

The distinction between biological and other forms of parenting

As today it is accepted and indeed widely advocated that infertile couples seek ART in order to cure their infertility, the age of the couples when they cease treatment often excludes them from adopting a child. Assisted reproductive clinics, whilst making it clear that the chances of success diminish with particularly maternal age, continue to offer hope to women who wish to conceive well into their forties (Susskind, 2004), thus limiting the alternatives to having a biological child. Age aside, many infertile couples choose not to pursue parenting by other than biological means. The whole concept of a biological child was irreplaceable for participants of this study. The reasons why they chose to try and conceive initially were not purely to add any child to their family, but *their* child. One co-created by them, a part of *both* of them, a symbol of their love and commitment to each other. This is exemplified by Andrea when she says '*I didn't have a craving for a child, so much that any body else's child would do.*'

Adoption differs substantially from other forms of parenting using ART such as donor embryos or donor gametes as well. Widdows and MacCallum (2002) highlight such differences as being, most obviously, the gestational relationship

experienced in situations where a donor is used opposed to the lack of this tie in the case of adoption. The gestational relationship is also something considered extremely important to participants of the current study, and perhaps one reason that adoption or surrogacy was not pursued. For couples in this study, the entire experience of pregnancy and childbirth as well as child-rearing was considered part of their role in life. This is exemplified in Aimee's story where she states '*I've always wanted to experience pregnancy and I've never, never done that.*' Highlighted by Widdows and MacCallum (2002) were the personal benefits to women who experienced gestation and childbirth on the emotional ties between the couple and the baby. However, although the gestational relationship that may be experienced by using donor gametes or embryos has greater social advantages as conception is seen to have occurred naturally (Widdows & MacCallum, 2002), this method of conception is not without concerns.

Nachtigall, Becker, Quiroga, and Tschann (1998) report a perception by even those who choose this method of becoming a parent, that donor insemination carries a distinct stigma. The majority of parents of children conceived through donor insemination surveyed in the study by Nachtigall et al. (1998) did not plan to disclose that their children had been conceived by donor insemination. This lack of disclosure emphasises societal perception of DI as being a less acceptable form of becoming a parent. It was not purely the risk of societal disapproval that deterred most participant couples from using a donor gamete, but also the perception that their baby needed to be part of both members of the dyad. For example, Aimee states '*To have Carl's child, to perpetuate his line, I guess, you know. To have something that's a combination of us, I guess.*' Even with the more conventional ART methods there is an attached stigma as the ideal is to conceive

'naturally' (Letherby, 1999). Adoption and surrogacy also carry their own forms of stigma and societal disapproval, discussed by (Letherby, 1999), as they also denote a deviation from the norm of 'natural' and 'biological' parenting.

Initially participant couples accessed ART as they were unable to conceive 'naturally' and ART is proclaimed to be the 'solution' for not just infertility but childlessness. This technology often promises success rates that all but guarantee couples their own baby. However, in cases where the results of treatment are negative (i.e., the couple do not end up with the much sought after baby), feelings of failure at their inability to conceive naturally are compounded. Even with the best technology that has provided many couples with their 'dream baby' they are unable to 'achieve' the integral social requirement of reproduction.

Guilt and failure

Di Paula and Campbell (2002) point out that quitting is negatively received by society, and those seen to persevere are viewed favourably. Participant couples are often told, as revealed in Aimee's story, '*oh but there's other things you can do, don't give up*' when they inform people that they have ceased treatment for their infertility. Throsby (2004) identifies that 'giving up' is a personal, moral failure' (p. 15). 'Giving up' carries the same negative connotation as 'quitting' so being labelled a 'quitter' can only add to an already lowered self-esteem due to their 'failure' to reproduce.

Baldwin and Sinclair (1996) discuss how the origins of self-worth are dependent on what reactions from others we associate with success and failure. Socially, to be childless is a failure of reproduction. Initially, participant women felt that they had failed to contribute to society, as they were unable to bear a child naturally

and conform to the expectation of marital couples. Further to this, their inability to reproduce despite ART compounded the sense of failure felt by these women. One of the most dominant issues in the women's transcripts was 'failure' which is obvious when Aimee says: '*Because I thought, you know, the embryos are going into my body, it's my body that's failing us.*' The sense of failure carried by these women irrespective of the origin of infertility may be explained by Throsby (2004), who highlights the point that "once an egg is fertilised in vitro, male infertility is confirmed and the focus shifts onto the female partner" (p. 26).

In accounting for the time and money spent on attempting to achieve a 'pregnancy' why did these couples persevere? One explanation to this question may be (as Di Paula and Campbell (2002) found) that individuals with low self-esteem persevered longer at a task they had repeatedly failed at than those with high self-esteem, proposing that the failed task held greater importance for those with low self-esteem, in order to "remedy their deficiencies" (p. 718). Alternatively, in this case, the continued hope offered and the guilt associated with their 'failure' to conceive and carry a baby to term kept them enrolled in the technology.

A further explanation could be that perseverance with treatment is fuelled by media reports that praise extraordinary efforts by couples in their quest for a biological child. For example, an article in the *The Age* newspaper reports "It has been six years in the making but Lisa Banfield's determination to have a child has finally been rewarded" (Wood, 2003). Further to this the article states that "Overall the Banfield's have outlaid \$A250,000 to make their dream of having a family become a reality" (Wood, 2003). The intimation that time, money and determination is all that is required in order to overcome fertility problems is not

just misleading, but adds to the level of failure felt by these couples and potentially questions the commitment by those who do not achieve biological parenthood. For those who do persevere unsuccessfully with infertility treatment the sense of failure heightens: as acknowledged also by Throsby (2002), failure is worn by the couple and not technology.

Societal values and isolation

Family, friends and acquaintances often compound the sense of failure felt by these couples. Evidence of being a less valued member of society is demonstrated in participant couples' stories about many situations regarding their state of childlessness. Rosemary shares how she was devalued by her own mother, '*and she hoped I would understand but she was going to leave everything to my brother and sister who had children because she wanted to maintain contact with the grandchildren.*' In keeping with the theory proposed by Gruenewald, Kemeny, Aziz, and Fahey (2004), which suggests that situations that threaten an individual's social value or standing can have adverse effects on one's self-esteem, participant couples often experienced negative emotions. Couples who shared their stories regarding childlessness often felt judged and devalued by comments made by others. Sarah speaks of not only letting herself and her husband down but society as well. '*And that I've let him down, that I've let, you know, sort of, not only him but us down and life, society, everything, I just felt like a real failure.*' This sense of letting society down may be fed by the promotion of having children to assist economic health as endorsed in a Radio National interview (McDonald, Hakim, & Phillips, 2002), indicating an ideal fertility rate of two in order to produce the next generation of workers. Widely publicised speeches such as those given by Premier Jeff Kennett to a group of high school

girls suggesting that women are not reproducing sufficient children to maintain current population levels (Bryson et al., 1999) further serve to instil a sense of social responsibility in women to procreate.

Such familialist ideology reinforces the need to produce biological children as the pre-eminent way to contribute to society, reinforcing the common societal belief as well as the belief of participant men. This is evident in Carl's transcript where he states '*I guess the thing about procreation is that it is the point of us all being here. And so that ... it's always going to be there, because it was ingrained into me from such a young age.*' Economists and politicians who strive to instil a sense of responsibility in people to procreate for the good of the country further reinforce this ideology.

Current government policy also highlights the importance of contributing to society in the context of reproduction. That is, 'contributing' in reality means leaving children behind to sustain the economy and look after the elderly population. The promise by Mr Costello (7.30 Report, 09/12/2004) that the \$3000 maternity payment is going to increase reinforces the importance the current government places on becoming a parent.

Social contacts invariably became estranged when friends of participant couples had children. Children tend to enforce whole new social circles and events for their parents, and those without children are left out of the circle. For example, Sarah says '*No bad words or anything but she'd (friend) be going out with ... or having lunch with a mother, ... and she would exclude me.*' Women participants' exclusion by their friends resonates with findings of a study by Wirtberg (1999)

which found that childless women were left out and replaced as friends as they were unable to contribute to child-related conversation.

These childless couples came to terms with the realisation that they are not going to be a traditional family, and so their sense of family may change to include just the couple, serving to further isolate them. Anna says: '*And also because again there is only the two of you and you are completely embedded in each others lives all the time, you don't have anything else to ... you know, have a dog, but you don't have anything else to worry about. You just become this person that ... that's completely, you know, he becomes your life.*'

As a method of protecting themselves against feeling left out and devalued, as well as avoiding situations where they were constantly reminded of their 'failure' to procreate, participant couples isolated themselves from the 'normative' social circle. For example Aimee discloses, '*and quite often, you know, we won't go to sort of social occasions where there's too many kids around. Purely for self preservation.*' In order to positively adapt to their new narrative, participant couples needed to avoid certain situations. Wirtberg (1999) similarly identified that certain family-oriented gatherings are difficult for childless couples. Thus isolating themselves from these situations signifies an adaptation process that is ongoing for participant couples. However, isolation was only practical for some situations as participant couples constantly faced issues pertaining to their childlessness at work, whilst shopping, and in the media and politics.

Conclusion

The stories told within this chapter provide insights into the difficulties regularly faced by involuntarily childless couples. Participant couples' relationships with

friends and family were jeopardised due to a lack of understanding, and with the breakdown of social relationships, these couples came to rely more on each other for support. Also contributing to the isolation of these couples was a sense of failure due to their inability to procreate and the lack of societal acceptance regarding their decision not to pursue parenthood by alternative methods.

While couples who participated in this study endeavoured to parent a biological child, parenthood by other means such as adoption or surrogacy, although considered, was not a choice. The variety of reasons given for not pursuing parenthood by alternative methods confirms the difficulties a couple faces when considering this option and highlights that adoption cannot be used as merely a substitute for a biological child and is definitely not a ‘cure’ for infertility. The sense of failure felt at not becoming a biological parent may not necessarily reduce if a couple happens to adopt a child. The distinction between adoptive and biological parenthood is obvious and is highlighted in literature by Daniluk (1996) and Letherby (1999), which emphasises both personal and societal perceptions that biological parenthood is the ultimate achievement.

The sense of failure felt by these couples due to their inability to procreate negatively affects them in other aspects of their lives. With the ‘failure’ being such an obvious and public one, fear of further failure was common. This discussion highlighted the major issues for participant couples associated with ceasing treatment for infertility and remaining childless. Although this chapter has told of essentially negative experiences for these childless couples, the following chapter will highlight the strategies they used to combat these adversities and move on with their lives.

Chapter Six

TRANSITION

*Infertility is a long exhausting road drenched in tears
 A strong character is needed
 For me the pain will always be there
 Not so intense – but nevertheless – still there.
 I've virtually come to terms with it now
 I feel contented, tranquil and oh so happy
 But very occasionally
 It rears its emotional head
 And I'm dramatically struck down.*
(Pamela Newman, 2001)

Introduction

The preceding chapter presented participant couples' stories about ceasing treatment for their infertility in the absence of a biological child. The previous chapter also encompassed participants' accounts regarding their decisions to not pursue parenthood by other means such as adoption, and the emotional and social consequences associated with these decisions. This chapter continues the stories of participant couples and describes the transition of coming to terms with the reality of living without children in their immediate family. In order for these couples to move on with their lives they find a focus on things other than their reproductive capabilities.

These couples charted a different narrative, one that is different from the norm of marriage, children and the future they had once thought they would have. The hope they had previously invested in living the normative narrative meant that, in some cases, couples' whole lives were mapped out to accommodate a lifestyle

that included children. When it became obvious that they were to remain childless, these couples needed to restructure many areas of their lives.

Committing to a new life and redirecting creativity

Filling the gap

With ART being an all-consuming process, few of the participants had time for other interests or careers. Upon ceasing treatment this became problematic, as couples needed to find something else to occupy their time. They described a sense of emptiness, of something missing in their lives, a void that needed to be filled by something else:

Sarah (p. 20-21): I just think it's sad that ... you know, you are on the edge of society and you're forced to live ... well live a life that that's not a life. Like, if you come across women without children, whether it is a conscious decision or whether it's forced upon them, you always find that they're workaholics or ... because they have to fill that gap, that maternal instinct or whatever it is, it has to be filled somehow. You'll never find that they're not passionate about something. And whatever they do, they do 130 percent, you know, it's all in. I just find that's sad. And I think it's because you're trying to run away and make yourself busy so you're not put into a vulnerable situation. And also because you do lock yourself into isolation, that you've got to have something to give you satisfaction in life without too much involvement with other people. A lot of people get satisfaction with emotional attachments and involvements, where that's been taken away from us, so we've got to replace that with something that's unemotional and it's usually either art or work or some sort of passion. I find that really interesting. But I think it's not healthy, and I know my life isn't healthy, it's not good to be like that, but there's nothing ... I don't know what the answer is.

Sarah suggests that she isolates herself to avoid feeling vulnerable regarding remaining childless. Rosemary also mastered avoiding situations where her childlessness would emerge as a public issue:

Rosemary (p. 13): We had the usual things, Mother's Day and Christmas, I don't like very much. I don't like to notice the television too much in the weeks (that) lead up to that. Um ... I don't like people handing me their babies to hold, as though there somehow will sort of be an inoculation shot or something and make me feel better for five seconds. I become very adept at avoiding those situations, I can see them coming. So I just ... I can do it very smoothly now, you just sort of absent yourself from the group. Yes, or when people come and say to you, 'oh so and so's pregnant, isn't that wonderful?' And I say, 'I'm sure it is for her.'

Although resentment is obvious in Rosemary' story, she discusses the way in which it is now possible for her to look at people with children and see both the benefits and negative aspects of parenting. However, there remains a sense of protectiveness about her situation, possibly due to past judgments regarding her childlessness, where she acknowledges that statements made by others pointing out the benefits of childlessness would not be appropriate or well received:

Rosemary (p. 20): And sometimes now, again with the passing of time, we can look at, you know when you see a child in the supermarket throwing a tantrum or you know something along those lines, you think, yep I'm not sorry that we missed out on that. I don't think I could have done that eight years ago but I can definitely do it now. Thinking, I don't want to know that at all. Or if you're at a restaurant or something and occasionally you see children at restaurants who are remarkably well socialised, I don't know why but ... they're very impressive in terms of being polite and sociable but there are some who are a nightmare and ah are just completely socially unaware. And I guess most children are at some stage, but say all the wrong things, many of which may embarrass their parents publicly. And when you see those things happen, you think, yeah glad I'm not having to go through that either. And also, on a more sobering note, when you see people who've had difficulties, particular with teenagers, and I'm sure that young children can have their difficulties but it seems that with teenagers some of the mistakes they can make can have life-long implications. That must be worrying. We see it in friends – concern – and you think, yeah, I ... it would be difficult having those concerns. So it's interesting, I guess with the passing of time you can see the ... you have a more balanced view of maybe what it would have been like to have been a parent. And there are some things you're

very happy to have missed. And there's a certain lightness, I guess, of not having to have had to worry or be concerned about those things, or to be ... have felt responsible for things that happen. So it's nice to be able to look at the upside of not having children. Which is interesting, because we can do that privately, but we wouldn't really appreciate anyone else pointing that out to us, isn't that interesting? I guess we sort of think that's glib coming from other ... it's a judgment I think you need to make for yourself. It's like, you know, we shouldn't be able to tell people that having children is good either; you know, that's a decision they need to make that for themselves, each person needs to make it themselves. So that's, that's ... it's good not to have to worry about some of those things now. Even though there's some sadness in not being able to share in some of the good things too. But at least we're not looking at it in a narrow way now.

What emerges in Rosemary's story are the various and continuing stages of life and the continual need of involuntarily childless couples to adapt to ongoing issues. That is, throughout the 'ideal' lifetime, children grow up, get married, and have children. Those children grow, achieve, and continue the life cycle. Therefore those who are involuntarily childless must come to terms with witnessing and continually adapting to situations that emphasise the reality of their childlessness:

Rosemary (p. 15-16): I think one reason why I fell into this black hole, that's the only way I can describe it, was it was finally having to confront the fact ... like if I was on treatment, that was when I had hopes of having a child and to know that I wasn't going to be having any more treatment, meant that we finally had to confront the reality that we would never have a child. And that proved to be extraordinarily difficult to come to terms with. I was embarrassed that it had hit me so hard. I thought I was better at coping with things than that. It's about undermining your self-confidence as well. And when I thought it through later, and about me pulling out of uni, I thought if I could do this again ... if I could do this again, I'd do it differently, and what I would do, and if people ask me about it, I say, well, I understand that being on treatment necessarily involves pretty much a total commitment, particularly if you're working full-time as well. You really just don't have time for a lot of other things, so there's a practical necessity there. But that's all I was doing, plus being involved with the support

group. So when I stopped treatment I had nothing to occupy my time, which is probably not a smart thing when you're feeling really down. And if I could do it differently, what I would do is find something, not necessarily anything too demanding but something that I had an interest in and I'd start doing it, so that if I had to make a decision to finally quit I could just throw myself into this other thing mechanically, I wouldn't have to go about setting it up. And I realised that when I went back into uni with just one subject, I realised I needed to find other goals. I needed to find other reasons for living, you know, I just needed to find other goals. Because being on a programme requires you to be extremely task focused and goal oriented really, sort of, to be committed to the process. It was like, if I didn't have that to do, that was what I'd been doing for 12 years. What else was there to do? And when I went back to uni with that one subject. I thought this is what I have to do, I have to find other things that I can be committed to and that I can believe in.

Apart from representing the dedication these couples had to treating their infertility, Rosemary's story illustrates the cost in terms of years lost whilst pursuing the dream of a biological child. Years spent in vain at the expense of possible careers or social interests cannot be reclaimed. Aimee too acknowledges the effort required to participate in ART and tells of the necessity to channel that energy into something else after the cessation of treatment. As well as creating a new focus for their lives by setting new goals, participant couples also maintained significant investment in their relationships:

Aimee (p. 16): Well, I've had to find other things to fill my time in. That's ... or to take ... I think to, to put my energy into. That's been ... that's been, like finding hobbies, something to do. Um ... because we put so much energy and time into trying to get pregnant ... um ... that we've still, I mean, we've still got that energy, we've just got to find something to put it into. So, I mean, one thing with the IVF ... um ... I mean I started doing my uni course during IVF. And that was my one thing that I think kept me sane. I started ... um ... a couple of new hobbies, which has been good. Um ... what else? We sort of, we're very, I think, conscious of doing, doing things that make us feel good. Um ... you know, like we still spend a lot of time together, we'll do things together that we enjoy doing.

You know, even if it's just going out looking in the shops or something, or going for a drive, or whatever. We're sort of making sure that we do stuff like that. Because with the IVF a lot of the time we'd sort of, we'd be too tired ... emotionally and physically to sort of do anything. It was usually only at the end of the IVF where we'd sort of do anything to sort of perk ourselves up. So we're sort of trying to do that all the time. Um ... we're actually getting into investment property, something which we never thought we would have done. We're planning on travelling ... um ... yeah, just I think really concentrating on stuff that we, I guess, never thought we'd do. But now that we ... we've sort of got that opportunity to do it now.

The acknowledgement by Aimee that the extra time, funds and energy available to them upon ceasing IVF and remaining childless created 'opportunities', signifies that she is focussing on positive aspects of their situation and therefore moving on. Whilst some participants dedicated their newfound time and energy into further studies and pleasure, others focussed their attentions on work. Many participants stated that they achieved more in their careers than their colleagues who were parents. James demonstrates how this is possible:

James (p. 8): I think I've devoted a lot more time to my work than what I would have done if I'd had children. Because it's funny when you've even got pets, when you can start and feel a bit guilty about not spending enough time with them. So, you know for sure that ... ah ... that the ... you know, the level of time, the amount of time you spend at work and the level of commitment you've got, you would just not ... it wouldn't be possible if you weren't able to be ... if you had children.

Sarah's story however has a slightly different tone, viewing her commitment to work as a way of avoiding situations and people as a defensive measure against things people say that may have a negative impact on her self-esteem:

Sarah (p. 3): I'm probably not ... I'm definitely not the same person I was, definitely not. Whether I'm a better or a worse person, I don't know, but I'm a different person. And like now, nothing touches me, like it's very, very hard to get

through, anything is not as important any more. Nothing affects me. Also, I think, I have probably delved into work more than I should, I've become a workaholic. So that I fill up my life with other things rather than living my life. And I feel too ... I don't want to expose myself to time ... thinking of spending more time with people because I'm still too vulnerable or something, or I'm not a complete person, so yeah, I'm a very, very different person. It's (remaining involuntarily childless) had a dramatic affect. In some ways it's good because I'm stronger ... as a person and I'm more driven, more determined, but I just think that softness is... something's missing. I'm basically a very sensitive person, always have been, and I've had to build a barrier to overcome that. But I think the sense of failure has made me like that too. I feel guilty as a person and a failure as a person. So you have to build the barriers around that so you're not exposing yourself to any situations where people make you feel guilty or feel that you are a failure, so I run away, or work or spend my time in an environment that that's not going to come up.

Andrea conveys how time has made a difference in how she perceives herself:

Andrea (p. 20): I was kind of very angry with my defective body and of course it touched on my womanhood. But I don't feel like that any more. As I said, it's kind of like it's really different paths. I don't feel less than ... there might be instances where people might make me feel ... but I don't take that on board. And it's kind of like my creativity, my ... all of that is kind if redirected. So, no, I feel like somebody whose had a different path, but not ... a woman who had a different path but not less of a woman.

The way in which Andrea has been able to redirect her creativity is indicative of her positively adapting to remaining childless. Not only has she been successful at redirecting energy once reserved for the pursuit of a biological child, she is also able to deal with comments that she would once have found confronting or hurtful, no longer allowing them to have a negative impact on her.

Achievable goals

After the failure felt at their inability to procreate, the importance of setting and achieving goals was paramount to participant couples, as the single-minded focus

required to undertake ART gave them little chance to pursue further goals. Aimee shares the positive impact of ceasing treatment and being able to set and fulfill realistic goals:

Aimee (p. 17): It sort of takes a bit of that weight off your shoulders, I feel. I mean, we've got a bit of freedom, I guess, which is one thing I don't think we ever had when we were doing IVF. We had no ... um ... no real sense of freedom. You know, we were sort of locked in to doing this treatment, for this goal, and I think one thing now, we can actually set goals that are achievable and go out and do them. And get ... I guess that sense of achievement through doing things like that, you know, where I think as with having kids ... um ... we'd be ... I mean we'd still have goals and achieve them, I guess, but they'd be very, very different. Um ... we've got goals, both individually and as a couple that we want to achieve, and we can do that now.

In addition to changes in work, study and recreational activities, some of these couples also found it necessary to make changes in their living environments in order to help them adjust to remaining childless. Anna's story explains the reasons for such lifestyle changes, sharing the reasoning behind moving out of an area that constantly reminded her and her husband of the absence of children in their relationship:

Anna (p. 19-20): On the other side of us our old neighbours had moved and the new couple had moved in and she'd just had a baby and the girl across the road had just had one. So our little quiet street where there were no children and kind of just parents with ... old people who's kids had grown up or people who had already children that were like ten or twelve, which with the neighbours on the other side. All of a sudden changed into this kind of, you know, new mothers club thing and another girl a little bit further down had had one too. So that made it really hard, that was ... so day to day that was really hard. Because I could hear babies and whatever, that was one of our reasons that we decided to move and then we wanted to do something different and Derek wanted to get out of ... I mean there's many implications of what ... you know, we'd renovated our house ... it was a beautiful, you know, three bedroom Edwardian house in a good area,

um, you know, it had the extra bedroom for the children. You know, it was all that. So we just felt like, what have we been doing for the last ten years, you know. And ... so we needed a change and we needed to do something.

Making a difference

One common link throughout men's stories was the determination that they would contribute in some way to society and leave behind a legacy. This was commonly referred to as 'leaving their mark'. James describes the importance of being a positive influence and states that even though he will not have his own children he can contribute to the lives of the children he teaches:

James (p. 11-12): Thought about that in the sense of ... ah ... um ... I guess it's just the capacity to live on, which is what you get through children isn't it? When you've got your own children. I think I've probably thought about that in terms of influencing others and having input into the lives of children now and seeing the sort of ripple effect that can happen. Like being positive with kids, or ... praising a child and seeing and knowing from your own childhood the impact that that had on me when I, you know, had some positive experience with a teacher or principal or something and then you ... so you know how that can be really, have a really positive effect. So I think I probably feel as though that's ... that I would be my ... um my last years I'll be able to look back and sort of say, well I've been ... I've influenced some lives in a positive way, even though I haven't had my own children. And that's not going to be quite the same, I don't think, because there's ... that would be something I, yeah, from that ... I won't feel as though I've been totally robbed of having that ... that enjoyment, or that my life's been a waste. Because I think you'd like to think you've left it a better place than it was when you came in. I don't think that's the case for some, maybe not all of them. Yeah, I think I want to make a difference. And I think you can do that on a scale ... on a smaller scale and in a small way. It doesn't need to be a grand thing. And there are lots of opportunities when you work in school to be able to do that. When you're in a leadership position you can ... you can model the way that you'd like other people to be towards you and hopefully they then, you know, engage with other people in the same way. It's tough work with some of them, but ...

Something to nurture

Couples expressed a sense of having to nurture something in order to feel satisfied with their lives. For many of these couples, nurturing was experienced in the form of looking after a pet. Derek articulates the importance of a dog in their lives, not just for nurturing, but also to enhance their relationship and fill an empty space in their lives:

Derek (p. 9): Well, it's something to look after, which is important, and also a distraction for us ... too because, um, I can't ... For example, I can't give love and devotion a hundred percent of the time to Anna all the time, and maybe visa versa. If the dog's there it'll absorb all that, the bits that you can't give, which is really important. And um ... you know, it's just a focus for us to ... just to do things together in a way, like when we do go away we try and take him with us, like a family.

Justification for childlessness

Developing one-liners

Participant couples constantly have to justify why they remain childless. People not only devalued these couples because they were unable to have children, but insisted on delving to find out the reason or cause of childlessness. In order to refute the presumption that couples remained childless for so-called selfish reasons, the common assumption being to further their careers or gain more material possessions, these couples often found themselves making excuses, or explaining that the absence of children in their lives was due to circumstances beyond their control. With this revelation however, these couples were vulnerable to further ridicule due to the cause of their infertility:

Greg (p. 3-4): But you know it's just sort of one of those little barbs that really didn't help you know, your personal circumstances. And so you felt different, pretty well right from the start, there was no question about that. People did, I think, if they didn't express themselves in those tones, there was a sense that you

were different. And sometimes without knowing, of course these weren't people who were close enough really to explain the circumstances, and therefore it was difficult to sort of tell them, well why are you in this situation? A lot of them simply thought, 'oh well here it is, you know, the selfish couple or young modern couple that all their interested in basically is themselves, being selfish, earning money', whatever it is, however people perceive you. Was it important? Yeah, it was important because, as I say, you can maybe melt away in a broader community, and stay away from that kind thing, but in our circumstances it wasn't that easy to do, you were part of a very small type of community and therefore those kinds of issues matter and they did count. So, I guess from my perspective you had to sort of over-compensate in some ways externally. I'm not sure about Andrea, there are things that maybe you could ask her and what her perceptions were. But I found myself sort of making excuses, I mean quick responses to things like that, where 'oh, you know we lost a baby back at such and such a time under life-threatening circumstances', which shut some people up. So the thing is we let them sort of imagine what the cascading effects of that was. And so you sort of develop one-liners to sort of get you out of that situation. And both of us liked being with children. There was nothing that sort of made us feel uncomfortable, just sad and sorry that we found ourselves in those circumstances.

Within this story the societal presumption that married couples can and should have children is obvious with no acknowledgement that a couple may be infertile. This presumption leads to the justification process that involuntarily childless couples go through as part of their everyday lives. Initially they feel the need to justify the absence of a biological child in their lives. It was important for the couples who participated in this study to be perceived as being involuntarily childless rather than it being a conscious and deliberate decision. This infers that participant couples still believe the ideal narrative includes children. The compulsion to explain or justify that the reason for their childlessness is involuntary could be associated with the ideology discussed by Crocker (1999), that people may be less stigmatised if their deviance is viewed as not within their

control. After stating the involuntary nature of their biological childlessness, however, participants were often further pressed to justify why they had not pursued parenthood by other means such as adoption or surrogacy. This deviance is something that could be perceived as within the couple's control. So on the one hand they are absolved of the deviance but at the same time they remain stigmatised.

Dealing with questions

Whilst trying to come to terms with the concept of remaining childless, participant couples were constantly confronted by people asking for explanations for the absence of biological children in their lives. Couples felt extremely confronted by simple questions regarding their reproductive status:

Anna (p. 20): Um, I find it really hard when people ... immediately say, 'do you have any children?' I always hate that question, I hate meeting people that I know they're going to ask that. And I just say, 'no we don't'. Sometimes, you know, you say, 'no we weren't lucky enough, we weren't this, we weren't that.' Sometimes I want to say 'mind your own business.' You know, I mean, I don't ask them. It's pretty um, I don't know it's almost like it cuts the ... a little cut every time because you ... I don't, it's hard to ... it's hard to put into words. It's not like I ... I think immediately, no I don't, you know, and want to break down. But it still cuts a little piece in you that ... there's no, I don't. And you realise every time you say it that it's actually ... it's actually true. I think sometimes you still don't admit to yourself that it actually is true.

Participant couples learned to deal with questions regarding the cessation of ART differently. Whilst some avoided being questioned about the subject, others were forthcoming with information; however, it was perceived that when information was freely given, it was essential that there was no room for any opinion or response:

Carl (p. 16): If people asked me how the treatment was going, I would give them a ten-minute discourse on what's happened and why. Um ... I didn't want people to give me an opinion, I didn't want them to say, how about this or how about that. Um ... I would say, well we've actually ceased IVF and we've been doing it for seven and a half years now and we've put the big, we've put the hard yards in and we just really don't want to go on with it any more. It's no longer part of our lives. Um ... so I really can't think of a situation off hand where someone's actually gone, oh you can do this ... I don't give them the option, I don't give them the opportunity to tell me what I should be doing. Um ... whether that's cowardly or not, I don't know. Um ... it was just my decision, so ... yeah.

The way in which Carl fends off potential judgments of his situation is indicative of his confidence in his decision and his commitment to adapt to a different way of life. Being able to adapt to situations and deal positively with comments from others regarding their childlessness requires time and skill by these couples. Aimee discloses the methods she uses to avert conversations related to her ceasing treatment and the decision to remain childless:

Aimee (p. 19): And I've mentioned to her that we're not, you know, pursuing having a baby any more and ... um ... she's, um, still saying, 'oh but there are other options', which we've found that a lot of friends have said. It's very weird because you sort of, once you've made the decision, and then you tell people, 'no we're not doing anything any more.' 'Oh, but there's this and this and this.' And, I don't know if it's that people find it difficult to accept the fact that we've stopped. I mean, they didn't understand it when we're doing it, and now they don't even understand it when we're not. (laughs) So it's really, that's a bit frustrating. Um ... yeah so it's ... I've found that with a lot of friends, like even friends at uni, um, like I had one girl say to me yesterday, 'oh I saw this really interesting show, um, or I heard something about this new IVF technique'. And I just said, 'sorry I don't want to hear about it, we're not doing it any more.' And, (she said) 'oh, okay.' So she was ... I think she's got the hint now not to say anything.

It is clear in participants' stories that the resolution process is ongoing and in some cases some issues are not resolvable. The variable nature of feelings

surrounding issues of childlessness for participant couples emphasised the unfeasible ideology of simply ‘getting over’ something that has negatively impacted on their lives. Whilst it was not possible to permanently eliminate these feelings, these couples constantly learned to adapt to situations and deal with questions they found confronting.

Self-preservation

Rosemary eventually overcame feeling pressured into justifying why she remained childless and also ceased to feel obligated to become involved in events surrounding other women’s pregnancies such as baby showers. People’s expectation that all women will participate in such events does not change, with women being expected to be enthusiastic regardless of their reproductive status. Whilst attending such traditional events may provoke negative feelings for involuntarily childless women, their absence may serve to further alienate them:

Rosemary (p. 13): I don’t feel obliged any more to be ... to participate in the joy of other people. I wish them well, I’m really happy when another woman who’s infertile gets pregnant. And there’s some poignancy about that for me, but I guess the thing that I say often to people when I find out is, it’s really good when one of us wins, I mean, there is, you think it’s good when somebody wins. But usually there’s a sensitivity about that, and an awareness about that anyway. But I used to feel this really strong obligation to be sort of ... jump up and down and be sort of really over the top like people are when they find out someone’s pregnant. I don’t feel that obligation any more. I don’t want to be churlish and I don’t want to be uncharitable and I wish people well, but I absent myself from ... I certainly don’t go to baby showers ... I just absent myself from those sort of discussions. Um, yes, so I guess I’m more comfortable about ... and it took me years and years to just answer no to the question, do you have any children?

Refusing invitations to attend social occasions that are perceived as confronting for these couples, such as baby showers and children’s birthdays, is a method of

self-preservation used by some participants. The ability to be able to avoid situations that would provoke a negative response was something that was worked at continually. Even prior to beginning a new job Aimee considers the impact her declining possible invitations:

Aimee (p. 21-22): Another thing with the nursing, I've sort of been thinking about is that, I know it's a very ... like on some wards it's very social. And ... um ... like on another ward I was working, there was like a big baby shower thing and everyone was excited and I'm sort of thinking, gosh what if I'm going to be in that situation where I'm working on a ward and, I mean, I want to feel like I'm part of the team and part of the, I guess, the group, but I'm going to have to say in situations that... where I won't be able to go. And I don't want that to sort of alienate me. Yeah, do you know what I mean?

Presumptions and criticisms

Perhaps partially due to the fact that the couples often focussed their energies on careers or study and were seen as high achievers, they were constantly perceived as career oriented and childless by choice rather than involuntarily childless:

Sarah (p. 5-6): But I realised recently that even in the car club, this woman ... we were at a dinner party and she sort of said, 'well you know it's sort of like your choice not to have them, you're a career woman and if you choose not to have children', blah, blah, blah. And I just sat there and went, 'hello'. And that hurt me because I thought, 'why does she think that?' Because she was talking about someone else who'd had trouble. And she said, 'oh the poor thing she can't have children and couldn't have them, unlike you that has made a career decision, or a decision that you're career orientated rather than having family.' And I'm sitting there and this woman's saying this to me. And I'm saying, 'where did this come from?' And I was devastated, I thought, 'Why does she think that?' How could she just make that up and does everybody think that? And I think, 'Why, what have I done or said?' ... I mean I don't wander around saying, 'hey, you know, I went through all these years of IVF' ... because again I'm very detached, I won't, you know, sort of open up or talk to people. Because even if you do talk to people that have children and say, I was on IVF. They just go, 'oh',they have no idea what it is or it's about or why. They just go, 'oh', and that's it. So I

sort of think, well, okay. I was stunned, absolutely stunned. And I thought, 'you stupid, stupid woman, how dare you assume things about me when you have no idea.' So I just went outside and had a cigarette and thought, oh, thank God I smoke. And then later on ... again it made me feel guilty, what am I doing to make people think that? And at the same time I sort of thought, why do I care? And then that makes me more shut down with people, again. So what I'm finding is I'm running into this pattern where I'm unapproachable, detached and very shut down. Friendly, very friendly, very nice, but there is a line, a very definite line and nobody comes over that. So, it's not really healthy, because the older I'm getting the more I'm shutting down and closing off and moving away from people, pushing them away, which is not good.

Sarah's story illustrates her tendency to avoid confrontation to escape the judgments of others. Smoking gave Sarah an excuse to remove herself from present company at a time she felt she needed to escape. Due to Sarah focussing her time on her career as a way of adjusting to her involuntary childlessness, she was labelled a 'career-oriented woman' and received no empathy regarding her childlessness. This unjustified stigma causes Sarah to further disengage with groups in an attempt to avoid being judged. The fact that Sarah does not dispute the assumption that she was voluntarily childless, however, raises questions regarding whether the stigma you own is worse than the stigma bestowed upon you. In this situation, Sarah may have felt that being thought of as a career woman was more acceptable than the pity that was so obviously assigned to the other involuntarily childless woman.

Other judgments were often made regarding the reasons behind a couple's infertility and childlessness. Responses to these judgments varied depending on their content. Rosemary tells a story about questions and comments she has found to be particularly annoying and insensitive, and her subsequent responses:

Rosemary (p. 6): But there's a surprising number of people who feel that it's their duty to tell you what you should be doing with your life. And I'm ... it takes my breath away the number of people who do this, and reassure you with all the usual thing, it's just that you can't have a child and all of that. Or, yes ... I've had people say to me to ... one that I've found most difficult ... I've had a few people say to me, 'do you think that maybe God did this to you because it's enabled you to do all this other work you do?' And I'm thinking this through, thinking ... and I said, 'Well look I don't think the God of the universe needs to go around inflicting people with infertility to get them to do things'. It doesn't strike me as all that logical. And ah ... and then some will say, 'oh it's all for the best,' whatever that means. And one poor unsuspecting person had me respond, 'I wonder if you would say that to the parents of a young child with leukemia. Don't say it to me. ' It sort of silences you. I think people don't know what to say. And I don't think those things are meant unkindly but it's sort of like silencing you. It's like you shouldn't really have anything to complain about, because we don't ... I think infertility's not visible. It's not visible like a sore arm or ... you're lucky you don't have cancer. Like the only reason that you should be in pain is if you're dying shortly, or you have a life threatening illness. It's sort of a criticism almost, implied criticism, which is ... which is another reason why I think you disconnect. You learn that people don't understand, so you don't expose yourself to telling people things. The only people that you really end up being open with are other people who've been through the system. Because even though they might not have had exactly the same experience as you, you have this expectation that they won't judge you about anything. And you need that freedom. There's something about that freedom of being able to be yourself. Even, sometimes with complete strangers. That's very freeing and ... I don't know, there's something very, almost therapeutic about it.

The freedom of being able to be yourself in the company of other infertile childless couples was frequently mentioned in couples' stories. The freedom was felt on a number of levels. People who had like experiences would not ask insensitive questions regarding childlessness or reproduction. For most participant couples, simply not having to answer the questions 'Do you have children?' and 'Why not?' which are common conversation starters, was refreshing. Meeting

other involuntarily childless couples also meant that these couples were being placed on an even playing field and therefore felt less guarded about fending off devaluing and insensitive remarks. Sarah gives a further explanation of why she no longer seeks friendships with women who have children:

Sarah (p. 15): And even other friends that I had along the line, once they had children, because again they get into the Mother's Club and kids going to school, we just drifted apart and so that pattern made me go, okay, I'll stay away from women that have children because it's too painful and too hurtful. Whether they ... I'm sure they didn't consciously mean it that way or for it to happen that way but they didn't know how to deal with it. And whether they tried to save me or throw me in the deep end, it hurt me either way, so it was a no win situation, it was very hard.

Positive aspects of childlessness

The best of both worlds

Throughout the stories shared by participants, many positive aspects to not having the responsibility of children were illuminated:

Alex (p. 8): Yeah, I mean, we can just ... I mean Sarah's come home on a Friday and we've just decided, looked at some property in Queensland and said, oh, all right, rung up and within two hours we're on a plane to Queensland. You know, just decided, oh all right. You can't do that if you've got kids. You know, just go up for the weekend and come back Sunday. Nothing changes, I mean you just go up, look at some property, came back. And you think, we couldn't have done that with kids. You get a lot of positives, I suppose.

Alex discusses other advantages to not having children as being able to enjoy friends' children without the responsibility that accompanies parenting:

Alex (p. 9): I had a mate and you know I used to take his little daughter out, she was only about six or seven and she'd be up early in the morning, lives up [in the country], and I'd get up early in the morning and the parents were still asleep, so I'd just write them a note and take her down and go and have pancakes at McDonald's or something. And she'd sit next to me on the lounge watching telly

and that. But I thought that ... that's cool. I think ... this probably wouldn't happen all the time. You're only seeing the best of, you know, ... yeah. It was nice, but you know a couple of days and I think that's nice and I'll get back to my life now.

Alex presents a realistic view of parenting by acknowledging associated hardships. Although this is in stark contrast to the idealisation of parenthood expressed by participants earlier, it is not a conflicting view as much as one shared intermittently dependent on time, context and the participant's emotional state.

The strong dyadic bond

Due to the loss of friendships and self-preservation measures employed by participant couples, they were drawn together for both social and psychological support. This situation placed these couples in a position of relative isolation from others in society. Reasons given for this necessary closeness and isolation from others was that partners understood what their spouse was going through when no one else could, and that this isolation was a form of self-preservation. These couples spoke of the difficulty of coping with observing others who were pregnant or had children, and therefore avoiding situations where they may have to publicly deal with these feelings. Due to this isolation, the relationships of these couples became closer. Remaining childless resulted in a sense of loneliness and emotional hardship, which once again results in a strengthening of the bond between them. There was an obvious reliance on each other for the support and understanding required to work through this difficult transition. Greatly contributing to the sense of loneliness was the breakdown of relationships with friends and, in some cases, family as well.

The couples perceived their relationships as being very close, with the closeness attributed to the shared experiences of being infertile and remaining childless. The reliance or dependence on each other as a sole support was seen to augment the couples' relationships and is consistent with research by Kearns and Leonard (2004) who conclude that interdependence in a relationship strengthens the dyadic bond and therefore enhances marital satisfaction. Sarah shares the impact that remaining childless has had on her marital relationship:

Sarah (p. 14): It's (remaining childless) probably made me too tolerant,...too accommodating,... because I feel guilty. And it's probably affected us in good ways because we're much, much closer, there's a very, very strong bond and an underlying bond that we can sort of literally ... he knows how I'm feeling, he is very supportive and very protective, because he knows how vulnerable I am and how hurt I get, and I don't show it, only to him. So there's that, that very strong bond there that wouldn't have been if we'd had children. It couldn't have been, no way, we wouldn't have had time. Yeah, it's had a varied affect, because.....I mean I'm very lucky because Alex's a very easy-going person and he's a very undemanding person. But I still recognise that I let him get away with too much, because I do feel guilty and he doesn't play on that, or he doesn't take advantage of it, but he does know that he's got a lot more freedom and scope than he should, or he would have, and he's happy with that. But that is one of the effects I think. But the upside is very much a very close bond, very much so.

Alex feels that remaining childless has had a positive impact on their marriage, emphasising the greater amounts of time childless couples can dedicate to each other and their relationship:

Alex (p. 6): Probably be more positive than anything else, that you spend more time together, doing things together, going places together. So you really get closer, I think, without kids. Yeah, for sure really. Not that kids drive you apart, but from what I've seen you have less time with each other than, you know, by the time the kids go to bed, sort of everyone else has two beers and that's it for them too, they've had enough. So, yeah, that's the positive one, you spend more time together, which can be a good thing or a bad thing I suppose.

Another factor that was seen to contribute to the strength of the couples' marital relationships was the fact that they had already survived one of the biggest challenges that their relationships could face, that is, their diagnosis of infertility and related treatments. Supporting each other through difficult issues related to childlessness and effective communication was considered integral to the strength of their marriage:

Aimee (p. 26-27): ...We feel like ... we've gotten through, you know, seven years of infertility, we can get through anything. It's like, it's easy from now on in a way. I mean there are both times when, um, you know, I'll sort of feel really down about it and we'll ... or Carl will feel down about, you know, he'll see a father walking along with a son or something and he'll sort of think, oh he's never going to do that. But we talk about it, we never let it bottle up. We always get it out and talk about it. Even if we're up till like two in the morning talking about it. We will talk about it and get it out in the open. Um, you know, have a cry, have a laugh, whatever. We support each other through it. So, if anything, it's probably made us stronger together. Um ... yeah, I don't think it's had any negative ... I ... for me I can't think of any negative thing. I mean, occasionally we'll have sort of ... the only thing I can think of is that, you know, if one of us sort of is feeling really down ... um ... you know, we'll talk about. We may not agree with everything that each other says but we'll talk about and get it out. I think that's, that's sort of kept us sane and together. (laughs) Yeah ...

As well as coming to terms with their childlessness as an ongoing and variable issue, participant couples were also able to make alternative plans for their future and see a positive side to remaining childless. The dominant factor in their ability to be able to cope and adapt to their childless narrative persistently involved their relationship with their spouse:

Aimee (p. 26): We're going to make sure that we ... um ... yeah, rely on friends rather than. Um, I've sort of thought maybe we'll have our nieces and nephews but the way things are going, I can't really see that happening. I mean, things may change, and I'd really like that, to be sort of part of their lives when we're old.

But, um, yeah, it's sort of, I think when you think about it, it makes you a little bit sad. Because you're not going to have children and grandchildren, you know, to I guess spend time with and watch them grow up and all that sort of thing. But on the other hand, we'll have each other, like Carl and I'll have each other. We'll be out, when everyone else is looking after their grandkids we'll be out doing whatever we want to do.

Sarah's story also illustrates the importance of spousal support in order to cope and accept a life without children:

Sarah (p. 12): And I just came home to Alex one day and I went, we're going away for three months. I said, if I don't I'm going to end up in a straight jacket, I can't take any more. I sort of had a breakdown, I remember I was out to dinner with the family. I remember Alex wasn't there, again I'd shut him out, and someone said something, I don't even know what it was, and I started screaming and bashing the table. I had all bruises all over my arm and just this terrible scream that came from I don't know where, and then I cried for about four days straight. I got over that and I said to Alex, that's it, we've got to get away, I've got to get away. And so we went overseas for three months travelling. And someone said to me, I think it was my sister, she said well you either come back inseparable or separated. And we came back inseparable, and it was the best thing, because we just had to get to know each other again and get close again and rely on each other again. But what I found really hard when we came back was having to part. You know, sort of spend time away from each other. But that saved us, that three months, and me. And from that point forward it was like, I was able to cope with a different direction in my life and accept it. That's when I accepted it and got on with it. And I thought, if I can't give him children, then I'll give him the happy little girl that he married, you know, if that's ... he kept on saying to me, I married you because I wanted to be with you. So I thought, well it's not fair of me to wallow in self pity and guilt, so I've made a conscious decision to close the book, accept it and give him back the person that he married and we've just gone from there. It's the best decision I've ever made.

Discussion

The major discussion points for this final findings chapter focus on the ongoing impact that remaining childless has on these couples, and the way in which they manage to proceed with their lives despite the adversity they encounter. The following subheadings are used to guide the discussion: grief, adversity and resilience, the dyadic relationship, and stigmatisation.

Grief

Unlike the death of a loved one, which is usually a shared experience among family and friends, grief related to infertility and childlessness is not typically a public affair. Secrecy and misunderstanding surround infertility and childlessness (Peters, 2001), so it is unsurprising that grief experienced by participant couples is poorly understood and rarely addressed. Grief theories pathologise grief that is ongoing, labelling it as ‘pathological’, ‘unresolved’, ‘complicated’, ‘chronic’, ‘delayed’, or ‘exaggerated’, and suggest that an individual who suffers pathological grief is likely to show signs of maladaptation (Dunne, 2004, p. 50-51). The reality of whether participant couples had suffered a major loss and therefore needed to grieve is not in question. What is debated, however, is the implication, if grief theories are to be upheld in this situation, that involuntarily childless couples will be maladapted.

Many issues for participant couples are complicated and as life is not static, issues these couples face cannot always be resolved completely. As further issues surface throughout their lifespan that constantly remind participant couples of their predicament of childlessness, they are placed in a position of constantly needing to adapt. Watching their peers who have children live the narrative that is

commonly accepted for couples provides a constant reminder of their inability to procreate. Every stage that is achieved by their friends' children potentially triggers a grief response. As the children of their peers grow and mature, issues for involuntarily childless couples change focus from their inability to parent a biological child to not becoming grandparents. However, it is not only developmental stages that may initiate responses to their childlessness; everyday social interaction is just as likely to remind these couples that they are living a different narrative. The inability to resolve all issues related to infertility and childlessness is highlighted by Rosemary when she says, '*I guess what I hadn't been prepared for ... that ... is this ongoing social context within which I was viewing my infertility or my childlessness.*'

There are problems related to remaining involuntarily childless throughout participants' narratives that require some resolution. These are often variable, however, so resolution is temporary in some cases. Participant couples periodically reflect on whether ceasing treatment and remaining childless has been the right decision. Also, couples intermittently found some situations confronting, particularly other women becoming pregnant, and birth. For example, Aimee shares her thoughts about her sister-in-law's pregnancy and impending birth in the previous chapter, '*his wife is due to give birth any tick of the clock, and even now ... I can't even bear to think about that. That just gets me ... really angry, upset, totally irrational.*' The variable nature of difficulties faced by participant couples is obvious as, despite their varying ages and the time lapsed since the cessation of ART, there was no significant difference in situations they found confronting. However, the intensity of their reactions dulled over time, and some things were reconciled but never forgotten.

Adversity

Throughout participant couples' stories it is evident that infertility and remaining childless has been a source of adversity. McQuillan, Greil, White and Jacob (2003) pathologise infertile women who are involuntary childless as having 'substantial and significant long-term psychological distress' (p. 1015). However, McQuillan et al.'s study used a quantitative methodology that does not allow for individual differences or the conceptualisation of experiences. A limited number of qualitative studies on the long-term impact of infertility and childlessness (for example, those by Johansson & Berg, 2005; Snarey, Son, Kuehne, Hauser, & Vaillant, 1987) concur with findings by McQuillan et al. (2003) and report that infertile childless women continue to experience substantial grief and remain hopeful of conceiving.

The disengagement with goals is necessary for an individual to adapt to their failure to reach a goal (King, 2004). The above-mentioned literature suggests that individuals who remain involuntarily childless may be unable to adapt to a different lifestyle and pursue other goals in life as they are unable to disengage from the unrealistic goal of having children. However, although talking about experiencing an intense loss, the couples who participated in the current study had disengaged from the goal of pregnancy and had made conscious decisions not to further pursue parenthood. As well as the disengagement that is required, resolution to grief involves reinvestment in something else (Watson, 1985). It was common for couples who participated in this research to reinvest in things like careers, travel or further education. However, the recognition by these couples that they were living against the normal narrative of society was illuminated throughout their stories. For example, Sarah states '*you are on the edge of society*'

and Andrea shares that being involuntarily childless is like '*sitting on a different side of the world.*' Participant couples strove to fit into a world where the normative narrative was different from their own.

According to King (2004), it is important that the new goals set are realistic and meaningful to prevent the detrimental impact of further failure. The importance of setting achievable goals after the unachievable goal of biological parenthood is exemplified by Aimee '*and I think one thing now, we can actually set goals that are achievable and go out and do them.*' This is echoed in the transcripts of participants in the previous chapter where they were fearful of further failure in their studies and work.

Resilience

Being able to relinquish the goal of pregnancy and parenthood after making such a substantial investment in the shared values of society and to reinvest in something else signifies resilience in these childless couples. Resilience is something that has not yet been fully conceptualised but has been defined as both a trait (Wagnild & Young, 1993) and as a range of processes (Rutter, 1999).

Martin-McDonald and Rogers-Clark (2005) define resilience as "the capacity to move through and beyond adversity" (p. 150), however, they also acknowledge that resilience is not "an all or nothing quality" (p. 151) and may take many years of personal work. This resonates with the vulnerability exhibited by Aimee where she shares: '*... like on another ward I was working, there was like a big baby shower thing and everyone was excited and I'm sort of thinking, gosh what if I'm going to be in that situation where I'm working on a ward and, I mean, I want to feel like I'm part of the team and part of the, I guess, the group, but I'm going to*

have to say in situations that ... where I won't be able to go.' Martin-McDonald and Rogers-Clark (2005) also propose that resilient people are not always strong when faced with adversity but gradually work toward overcoming this hardship. Although at the time of our encounter the cessation of ART was very recent for Aimee and her husband, Aimee is able to acknowledge the difficulty she faces in her work environment and is working toward a resolution of this problem. Also, varying stages of resilience are seen with Aimee progressing in other areas of her life such as her university degree and her career.

Walsh (2003) suggests that a key to resilience is 'acknowledging what can't be changed and putting efforts and actions into possible options' (p.56). This is apparent throughout participants' stories with their dedication to alternative paths in life after making the decision to cease ART and by enhancing their careers and taking up new hobbies. The concept of resilience as a process is further supported by participants' stories. For example, Sarah talks about the process of her coming to terms with her involuntary childlessness '*And from that point forward it was like, I was able to cope with a different direction in my life and accept it. That's when I accepted it and got on with it. And I thought, if I can't give him children, then I'll give him the happy little girl that he married, you know, if that's ... he kept on saying to me, I married you because I wanted to be with you.'*

Participants who had been able to disengage with ART when the decision to cease treatment was made and those for whom a significant time had passed since the cessation of treatment displayed more resilience than others. For example, Rosemary continues to hold a position in which she is very much absorbed with ART which impacts on her ability to move on and away from it. The difficulty she continues to have with accepting and joining in the common occurrence in

everyday life of other women's pregnancies and childbirth is obvious in her story where she says: *I don't want to be churlish and I don't want to be uncharitable and I wish people well, but I absent myself from ... I certainly don't go to baby showers ... I just absent myself from those sort of discussions.* However, Rosemary has shown resilience in other areas of her life, successfully completing a university degree and furthering her career.

Bonanno (2004) proposes that, due to the bulk of the literature available surrounding loss and grief focusing on psychological dysfunction, little is known about healthy adjustment and positive outcomes of such events. Bonanno (2004) refers to the term resilience as the ability of an individual "to maintain relatively stable, healthy levels of psychological and physical functioning" (p. 20). Further to this Bonanno (2004) states that those who are resilient are capable of generative experiences and positive emotion, and in contrast to those who simply *survive* hardship, resilient individuals are capable of producing a positive outcome from an essentially negative experience.

It was important to participant men to contribute to the younger generation or society in general. The very reason couples persevered with ART for so long was their belief that producing biological children is the pre-eminent way to contribute to society. This belief is expressed by Carl when he states '*I guess the thing about procreation is that it is the point of us all being here. And so that... it's always going to be there, because it was ingrained into me from such a young age.*'

Despite the adversity they had encountered, participant men recognised they were able to contribute to society without having children. This is apparent when James talks about his job as a teacher and says: '*....my last years I'll be able to look*

back and sort of say, well I've been ... I've influenced some lives in a positive way, even though I haven't had my own children.' The ability to recognise their potential to contribute to society in different ways points to the resilience of participants. Furthermore, Walsh (2003) suggests that resilience can be shown by 'transcendence: from personal tragedy and suffering to concern and action on behalf of others, to prevent similar suffering' (p. 56). By their contribution to this research, participant couples are contributing to knowledge that has the potential to change how infertile childless couples are viewed and treated, thus potentially preventing suffering.

Resilience is shown by these couples to be a process. That is, participant couples for whom greater time had elapsed since making the decision to remain childless showed greater resilience than those for whom this decision was recent. Greater resilience was also evident in participants in this research who have been able to completely disengage from ART compared to those who are still involved in some capacity with this technology.

Walsh (2003) acknowledges the importance of strong relationships to resilience. Furthermore Ben-David and Lavee (1996) and Beitin and Allen (2005) found that couples who had faced adversity together relied on each other more, resulting in the strengthening of their relationships and therefore resilience. This is congruent with participants in the current study. For example, Aimee says: ... *we've gotten through, you know, seven years of infertility, we can get through anything. It's like, it's easy from now on in a way.* Strong relationships may therefore have contributed to participant couples' resilience to adversity.

The dyadic relationship

Wenger (2001) found that childless men and women who were married had very close relationships and were dependent on each other. This correlates with the findings of the current study. Wenger (2001) studied differences between childless men and women and those who married or did not marry (p. 82). Wegner (2001) acknowledges that parenthood was more gender specific in the generation studied, so looked at men and women separately. Times have changed significantly regarding women and their careers. The women who participated in this current study all had professional occupations, contrary to childless married women in the study by Wenger (2001) who were born many years earlier (1888–1913). Adapting to remaining childless for these populations holds both differences and similarities. Whilst a large percentage of childless married women in Wenger's study had not worked after they married, the women who participated in the current study used their careers to assist in adapting to their childlessness. Similar to the current study was the evidence of a closer relationship between husband and wife due to their childlessness.

Kearns and Leonard (2004) found that social support and socialising as a couple rather than independently enhanced the dyadic relationship. Kurdek (1993) highlights the importance of interdependence in the dyadic relationship to enhance marital satisfaction, stating that one partner's low level of dependence on the relationship shows negative correlation to marital satisfaction. These childless couples being dependent on each other for support in many areas of their lives may explain their reported closeness and increased marital satisfaction. For example: *Sarah: 'And it's probably affected us in good ways because we're much, much closer, there's a very, very strong bond and an underlying bond that we can*

sort of literally ... he knows how I'm feeling, he is very supportive and very protective, because he knows how vulnerable I am and how hurt I get, and I don't show it, only to him.'

Peterson et al. (2003) found that couples who felt similar levels of social stress related to insensitivities about their infertility, or infertility-related isolation from family and friends, had higher levels of marital satisfaction compared to couples who reported varying levels of experience of stress. Peterson et al. (2003) elaborate by proposing that couples who agree on stress levels may deal more effectively with stress by supporting each other, thus leading to increased marital satisfaction. This mutual support provided within the dyadic relationships was evident in Aimee's story where she says: '*We will talk about it and get it out in the open. Um, you know, have a cry, have a laugh, whatever. We support each other through it. So, if anything, it's probably made us stronger together.*'

Burman and Margolin (1992) affirm that marriage may enhance one's ability to cope, either due to somebody providing coping assistance, or their presence enhancing one's own coping capacity. Also proposed in Burman and Margolin's paper is the suggestion that "although marriage does not ensure a healthy lifestyle, recognition of one's value to others may limit one's maladaptive behaviour" (p. 57). Although essentially referring to physical health and marital relationships this could apply just as well to psychological well-being. With this in mind, it is probable that being part of a couple is instrumental in creating positive outcomes for participant couples.

Stigmatisation

Couples' perceptions that they were stigmatised were obvious in many of their stories. Goffman (1963) defines stigma as the term 'used to refer to an attribute that is deeply discrediting' (p. 13) and elaborates that those stigmatised will sometimes go to extremes in an attempt to correct their 'failing', thus demonstrating the deleterious impact of stigmatisation. This is congruent with participant couples' attempts to 'correct' or 'cure' their infertility with ART. Not only did participant couples subject themselves to invasive treatments and procedures, they made many sacrifices striving to become 'normal', that is attempting to eliminate their discreditable attribute of childlessness by becoming parents. With infertility and childlessness not being immediately apparent in many social encounters, participant couples become what Goffman (1963) refers to as *discreditable* rather than *discredited* as is the case with individuals whose *difference* or *discrepancy* is visible.

Goffman (1963) further discusses the concept that when we first meet individuals, we anticipate their 'social identity' based on first impressions and refers to this as a 'virtual social identity' as it may be very different to their 'actual social identity'. When this difference between a person's virtual and actual identity becomes apparent, Goffman refers to the identity being 'spoiled'. The presence of a spoiled identity is exemplified in Anna's story where she says: '*I find it really hard when people ... immediately say, 'do you have any children?'* *I always hate that question, I hate meeting people that I know they're going to ask that. And I just say, 'no we don't.'*' People immediately asking the question 'do you have children?' means that Anna's identity is instantly spoiled as her childlessness has

been ‘revealed’. If the question was not asked, Anna’s virtual social identity may remain intact, therefore hiding her discreditable attribute.

Participant couples’ continual justification of their state of childlessness correlates with Crocker’s (1999) theory relating to the controllability of a stigmatising attribute. Participant couples generally perceived that being involuntarily childless was more socially acceptable than choosing not to have children. This is evidenced by the careful choice of words often used when answering questions regarding their reproductive status. This is illustrated where Anna says, ‘*Sometimes, you know, you say, ‘no we weren’t lucky enough, we weren’t this, we weren’t that.*’ However, as stigmatizing attributes have situational dependence (Crocker, 1999) at times it was felt by participants that a stigma attributed in a social context was less alienating than the stigma owned. This is nowhere more obvious than in Sarah’s story where she conveys ‘*Because she (female acquaintance) was talking about someone else who’d had trouble (having children). And she said, ‘oh the poor thing she can’t have children and couldn’t have them, unlike you that has made a career decision, or a decision that you’re career orientated rather than having family.*’ Sarah’s decision not to correct the assumption by this acquaintance that she was voluntarily childless may be explained by the context in which the stigma was discussed. Although there is a stigma attributed to Sarah in this case – the stigma of childlessness – this attribute assists Sarah in concealing the further discreditable attribute of infertility.

Goffman (1963) highlights the point that during social encounters with a person who has a known or a perceived stigma, all parties experience uneasiness and discomfort, but as stigmatised people are subjected to similar encounters more frequently they become adept at managing them. Participant couples became

adept at managing social situations either by avoiding them or by taking control of subject matter that was potentially stigmatising. For example, when Carl is asked about ceasing IVF treatment he states: '*I don't give them the option, I don't give them the opportunity to tell me what I should be doing. Um ... whether that's cowardly or not, I don't know.*' Taking control of a potentially stigmatising situation in this way further signifies Carl's adjustment and adaptation to a childless lifestyle.

Conclusion

Literature regarding loss and grief has historically pathologised the grief process, concentrating on negative consequences of grief. However, more recently it has been suggested (by authors such as Bonanno, 2004) that resilience and positive adaptation may be more common as reactions to loss and grief. Although couples who shared their stories for the purpose of this study expressed obvious grief reactions, they also showed resilience in the way they were able to rise above the difficulties they faced and to create positive outcomes from remaining childless. Setting themselves achievable and challenging goals assisted couples to re-build their self-esteem and enhanced the process of adapting to their life without children. For these childless couples, the role of their partner was also seen as a critical component of this transition by providing support, friendship, love and understanding.

Chapter Seven

CONCLUSION

*I shall be telling this with a sigh
 Somewhere ages and ages hence:
 Two roads diverged in a wood, and I—
 I took the one less traveled by,
 And that has made all the difference.*
(Robert Frost, 1874-1963)¹⁷

This chapter provides a summation of the findings and outlines conclusions I reached from the analysis of participants' transcripts. In light of the findings from the current study addressed in this chapter are suggestions for care relating to the practice of health professionals and, as it is acknowledged that no one study is capable of addressing all issues surrounding such a complex topic, limitations of the current study are highlighted. This final chapter also includes the implications this research may have for nursing and suggestions for future research as well as a comparison of findings from recent research with a similar focus to the current study.

Summary

As previously discussed in the literature review, gender socialisation ensures that men and women strive to fulfill their gender roles and social responsibilities (Egan & Perry, 2001; LeBlanc, 1999). These social forces ensured participant couples accessed ART in an attempt to fulfill the roles of motherhood and

¹⁷ Last verse of *The Road Not Taken* by Robert Frost, 1874-1963, Retrieved April 17 2006 <http://www.poetry.com/greatestpoems/poem.asp?title=The+Road+Not+Taken&author=Robert+Frost>

fatherhood, and yet these same influences maintained their enrolment in the technology despite its chances of ‘success’ being minimal. Furthermore, the way in which we are socialised ensures a hierarchical structure that places biological parenting above other forms of parenting (Letherby, 1999), and thus further reduced these couples’ chances of successfully fulfilling their expected social roles.

Underpinning participant couples stories are expectations that these couples will follow societal norms and procreate or, failing this, will become parents by whatever means necessary. These expectations are fuelled by this normative narrative, held not only by members of society in general, but also by the couples themselves. The inability of participant couples to fulfill or live up to these expectations results in isolation, with the couple forced to depend on each other for support, understanding and in some circumstances emotional protection. However, throughout the hardships faced by participant couples regarding their childlessness, resilience was continually demonstrated across their stories.

In order to avoid being stigmatised due to being infertile and childless, these couples attempted to ‘cure’ their ‘failing’ by accessing ART. The availability of technology as a ‘cure’ for infertility placed further expectations on participant couples to pursue and succeed at biological parenthood. As Franklin (1997) illuminates, the hope associated with this technology extends to all members of society. Although assisted reproductive technology may be available, it provides no guarantee that all couples will be able to ‘achieve’ parenthood. Apart from the obvious fact that availability does not necessarily signify accessibility (as ART is a costly and time-consuming process and is not a viable option for all infertile couples), the success rates of such technology for many who access it remains

small. However, due to societal expectation that married couples will procreate, their belief in the ideology of the normative family, and their belief that the technology will work, participant couples sought a ‘solution’ to their childlessness via ART for many years.

As many ART services have varying definitions of ‘success’ (often disparate to those held by participant couples), and as statistics are manipulated to promote further patronage of ART services, the likelihood of ‘success’ is often overstated. The embellishment of ART as a successful cure for infertility is at least partially responsible for couples persevering with treatment for prolonged periods of time and often to the detriment of their health. As well as ART services giving unrealistic impressions of couples’ chances of reproducing a biological child, the giving of information pertaining to treatment, or at least the couples’ ability to comprehend this information, was negligible and fell short of the requirements for informed consent. This resonates with literature by Daar (2001), Gurmankin (2001) and Shanner and Nisker (2001) which will be discussed in further detail later in this chapter.

Lack of understanding related to ART procedures was not the only knowledge deficit that was obvious in the participants’ transcripts. Knowledge and understanding demonstrated by participant couples regarding the reasons for infertility as well appropriate treatment for these diagnoses was noticeably limited. Although responsibility for thorough and comprehensible explanation of diagnoses primarily rests with the referring doctor, ART services need to be held accountable for the giving of information and ensuring understanding of that information whilst a patient is in their care, and particularly when initiating treatments that may well have implications for the patients’ long-term well-being.

Under the umbrella of infertility are multiple causes that are not all able to be ‘cured’ by ART. At present, if a couple or individual is diagnosed with infertility they are commonly referred to ART services with the belief that they will be assisted in having a baby. However, most causes of infertility are complex problems that require a complex solution. And although ART is a complex solution, apart from being presented as a simple solution, it uses much the same treatment for a plethora of infertility diagnoses.

In fact, ART cannot provide the solution in many cases. Throsby (2002) acknowledges that whilst nature cannot be overruled by technology, ART service providers use this to dispute their high failure rates, stating that ‘naturally’ most embryos are rejected anyway (p. 51-52). ART cannot therefore be classed as a refined technology, as it clearly does not provide solutions to many couples. However, Rowan Ross, director of Sydney IVF (SIVF), disagrees and in discussing pre-implantation genetic diagnosis (PMG) is quoted as stating “it’s an improvement on nature. In the future you will have sex for fun, but when you want babies, you’ll have IVF” (Saville, 2004).

Childlessness is regarded as abnormal with the perception that ART will provide a curative solution. Therefore, participant couples, as well as not being ready to relinquish their goal, may have been reluctant to cease such treatment for fear of being labelled ‘failures at reproduction’ and stigmatised. Whilst in treatment the couples were immobilised, not able to move forward. As well as an inability to progress with their lives, couples were also unable to focus on goals that were a significant part of their pre-treatment narrative. The years spent pursuing treatment for infertility and childlessness rendered the couples in ‘limbo’, unable to realistically plan for the future due to the uncertainty of what their future would

hold. Putting their lives on hold whilst hoping and waiting for a child conceived with the aid of technology limited couples' options not just with unconventional methods of parenthood such as adoption, but also delayed the process of adapting to an alternative way of life without children.

The crushing disappointment felt by participant women in particular after many years of repeated 'failures' was deleterious to their self-esteem and finds support from Johnson (1996), who acknowledges that the loss of control and disempowerment can be attributed to the tenor of relationships with health professionals, as these impact negatively on infertile women's perception of self esteem. In order to move on these women needed to set themselves achievable goals so that they might feel good about 'succeeding' at something. With the constant reminder of their reproductive 'failing' in all areas of their lives, participant couples tended to remove themselves from situations they found confronting, often leading to isolation. By isolating themselves from situations they found difficult to face, participants' dependence on their spouses was increased. This dependence fostered closeness and a milieu of support, thus assisting couples to progress with their lives whilst facing the varying issues surrounding their childlessness.

Constantly emerging issues were something that participant couples learned to live with. At times they employed several behaviours, including withdrawal and avoidance, to assist them in coping with societal pressures. At times they felt the necessity to justify why they were not parents and at other times they chose to simply allow people to come to their own conclusions. Many of the strategies employed by participant couples were intended to fend off being labelled or

stigmatised by people. However, whether or not they were thought of as voluntarily or involuntarily childless, an attached stigma remained.

The way in which statistics are represented in the Australian Institute of Health and Welfare (AIHW) report has recently been revised and the definition of a treatment cycle has been broadened. The definition of a treatment cycle is now inclusive of all cycles commenced, including donor insemination cycles, cancelled ART cycles and unsuccessful oocytes pick-ups and embryo thaws (Bryant et al., 2004, p. 5). This new definition provides a more accurate and honest indication of success rates, which are much lower than indicated by statistics in previous reports. Although the revised definition shows some progress toward a more realistic representation of ART services, the problem of defining ‘success’ remains.

However, the information that is most readily available and accessible to the general population remains that supplied by individual ART services. Although clinics now advertise ‘individualised care’ and acknowledge that success rates can be misleading (Monash IVF, n.d), they continue to present success rates in terms of pregnancy rates (defined as evidence of a pregnancy on ultrasound scan at six weeks gestation and not just a positive blood test (Monash IVF, n.d)) rather than a baby to take home.

Suggestions for care

Hope and the promise of technology: realistic chances of ‘success’

This new reproductive technology which Rose (2005) refers to as a ‘hope’ technology, provided hope of a biological child to participant couples, thus initially enrolling them into this technology. This same hope was fed by society

and ART services themselves with unrealistic portrayals of their chances of 'success'. Hope, and the promise of biological parenthood served to ensure participant couples' continued engagement with this technology despite repeated disappointments. As predicting a couple's chances of conceiving and taking home a biological baby is dependent on many factors (e.g., age, as well as origin and type of infertility), recommendations are for ART clinics to address these issues on an individual basis. Individualistic consideration regarding a couple's chances of success will serve to encourage a more realistic expectation of treatment, thereby possibly preventing prolonged and futile investment in technological 'cures' for infertility and childlessness. If expectations of treatment are reduced to a realistic level, couples are more likely to be empowered to make the decisions required to pursue either an alternative way of becoming parents or living a different narrative from the norm and following other life aspirations without children. Furthermore, subsuming all causes of infertility under the one umbrella term becomes problematic. ART claims to provide a 'cure' for all infertility, irrespective of its cause; however, this is clearly not the case.

Unrealistic representations of success rates portray ART as a foolproof solution to childlessness. Whilst on the one hand, a couple's infertility may be momentarily 'cured' if conception occurs, on the other there is still no guarantee that their childlessness is also remedied because of correlated conditions at the root of their infertility. As complications of pregnancy are frequent in ART, professionals responsible for the delivery of care to couples need to discuss the very real risks of miscarriage, ectopic pregnancies, genetic malformations and premature births. It may well be argued that these complications may present in any pregnancy. However, where couples have accessed ART, the pregnancy is a direct result of

treatment delivered to a patient and therefore requires explanations of all possible outcomes.

Other options such as adoption or remaining childless should be canvassed on initial consultation and frequently throughout treatment. It is the responsibility of health professionals to ensure patients are informed of their options. Couples need to know it is always a possibility to not have children and that there are other ways of living a fulfilling life. The knowledge of alternatives to treatment may assist couples in making informed decisions regarding whether to commence or continue treatment.

Imparting information

Due to their willingness to satisfy their social responsibility of biological motherhood, participant women may have forgone their right to seek further knowledge regarding their ‘condition’ and all available treatment options. The invasive nature of ART needs to be emphasised to couples along with possible complications of these procedures. In light of information revealed in participants’ transcripts, where very few couples had an adequate understanding of their ‘condition’, procedures they had undergone and the long-term effects of treatment on their pre-existing ‘conditions’, it is recommended that ART services treat the couple holistically rather than purely treating their infertility. If treatment delivered for the purpose of assisted reproduction diverges from the commonly accepted treatment for an individual’s pre-existing condition, for example as in the case of treatment for endometriosis, then all information needs to be imparted to the couple to allow informed decision making regarding issues that may impact on their future lives.

The treatment of endometriosis and PCOS varies significantly for those who are attempting to conceive and those who are not. With the sole focus of ART being on ‘curing’ infertility, clinics pay little consideration to the long-term health concerns of these women. In order for women affected by these diseases to make informed choices about their future health, the focus of their care needs to be holistic and individualised, with options that do not simply include treatment for their infertility but also options of treatment that assist them in stemming the progression of these diseases whilst providing optimal pain control, rather than exacerbating the condition. Evidence that drugs and hormones given as part of the ART process may aggravate conditions such as endometriosis and PCOS is at present anecdotal but worthy of consideration.

Independent counselling

The very nature of infertility and its effects on individuals, as well as its associated social significance, suggests the necessity of counselling services for those undergoing treatment with ART. The FSA RTAC (2002) recommends the appointment of experienced infertility counsellors to ART services and outlines that they need to be available at various stages of the IVF cycle. However, the appointment of such counselling services fails to address all issues involved with treatment and provides inadequate services for those who may have difficulty returning to the ART clinic after a failed cycle or who have a problem with the ART service to which the counsellor is attached. In this case, the obvious conflict of interest may lead to biased advice. For example, the attitude of Carl and Aimee’s counsellor that they were not ready to make the decision to cease treatment at that stage. Counselling should be provided by a service that is independent of the clinic to prevent possible conflict of interest. As it stands it

appears that counselling exists for the legal protection of the clinic and not the patient.

Although Rose (2005) points out that pre-implantation genetic testing may result in the devaluing and further stigmatisation of those with certain conditions, he also acknowledges certain benefits. Genetic testing for multiple miscarriages or a family history of miscarriage may provide couples with an explanation for their infertility that may otherwise remain unknown, or be discovered after a pregnancy has occurred, thus possibly leading to a heart-breaking decision by the couple as to whether or not to undergo a mid-trimester abortion as in the case of Anna and Derek. In providing this service, however, appropriate genetic counselling is also required.

Available counselling

When planning this current study, it proved difficult to provide participants with access to counsellors in the event that they may have become distressed. Initial contact with one infertility counsellor whose details were found via a simple internet search proved fruitful, with the counsellor in question agreeing to consult with any of the participants who wished to contact her, either prior to or after the sharing of their stories. However, as the ethics committee required further services so that participants may be given a choice of counsellors, the difficulties associated with accessing counsellors with experience in infertility counselling became apparent. Apart from having a website dedicated to the Australian and New Zealand Infertility Counsellors Association (ANZICA), there was scant reference on how to access infertility counsellors. The telephone numbers provided on the website were invalid, and when eventually a current phone number was tracked down, names and contact details of counsellors were

withheld due to privacy issues. For the purpose of finding counsellors for participants to access, I was advised to leave my name and details with the person contacted (an administrative assistant, not a counsellor) so that an infertility counsellor was able to make contact if it was felt that the request warranted further correspondence. After attempting contact in this way several times without success, I abandoned this method of contact. The availability of counsellors independent of ART clinics remains inadequate to provide effective and timely care for couples who require such services.

Nurses as counsellors

Nurses who are employed in the area of ART, due to heavy workloads and lack of counselling experience, are ill-equipped to deal with the emotional, psychological and social problems experienced by the infertile couple (Imeson & McMurray, 1996; Kuczynski, 1989). The criterion used for the purpose of employment at most infertility clinics includes the pre-requisites of midwifery training or prior IVF experience¹⁸ (FSA RTAC, 2002). In view of the independent statistics that show that only a limited number of women who access treatment can expect a pregnancy, and that responsibility and care delivered by ART services rarely extends beyond the confirmation of a pregnancy, the qualification of midwife would seem unnecessary. Nurses would be better equipped for this type of nursing if they had specialist counselling skills.

The Australian Nursing Council Inc. (ANCI) Competency Standards for the Registered Nurse stipulate that nurses must give competent and holistic care which includes effective communication and the ability to provide support to

¹⁸ N. Fuscaldo, personal communication, August 24, 2001.

clients experiencing emotional stress (Australian Nursing Council Inc [ANCI], 2000). However, couples who are undergoing treatment for infertility may require more specialised counselling. Recent guidelines from FSA RTAC (2002) state that the nurse's role in ART includes counselling but lists no postgraduate counselling qualifications as either essential or desirable in their guidelines for the accreditation of nursing services. Although the services of a specialised counsellor are offered at most ART clinics, the nurses deal with these couples firsthand and are better situated to communicate with them and determine any problems they may be facing. At all but a few Australian ART clinics there are only one or two specialised counsellors available for a multitude of clients accessing ART, making effective counselling for all clients impossible.

Nurses working in the area of ART should be well prepared to at least act as a referral service for those couples who may not be empowered to initiate counselling procedures independently. Research such as the current study may provide nurses with heightened awareness of the possible experiences of these couples, thus leading to more sensitive care and timely referral. Van Manen (1990, p. 6) states, "We can only understand something or someone for whom we care". With this in mind and the fact that nursing had long commended itself on being a caring profession, information that enhances understanding of these couples will hopefully encourage nurses to improve or change their practices for the benefit of their patients.

Follow-up care

To date, ART services have shown minimal interest in clients beyond either conception or a negative pregnancy test after an embryo transfer. ART clinics may improve care delivery by providing follow-up services to individuals and

couples irrespective of the outcome of treatment. This may prevent clients feeling isolated and abandoned, as described in Anna's story, and may provide the opportunity for support and counselling in the event of a negative outcome of treatment.

Accountability and Consent

Throughout the participants' stories, it became evident that their knowledge about the procedures they had undertaken or the treatments they had been given was sketchy or limited. This may have been partially explained by the length of time that had passed since ceasing ART treatment. However, those couples who had recently ceased treatment also demonstrated little understanding of certain procedures and treatments. Another explanation may be the elimination of such essentially negative experiences from their minds. In a recent study on patients' understanding of their treatment plans, Makaryus and Friedman (2005) found fewer than half the participants could identify their diagnosis, their current medications, or the purpose or major side effects of their medications. Makaryus and Friedman (2005) propose that effective communication and time spent to ensure patient understanding of treatment may positively impact on health outcomes. A lack of understanding of treatments and diagnoses by patients is not an uncommon occurrence, and may be due to a lack of information given to them or an inability to reliably recall information (Murphy et al., 2004; Ong, de Haes, Hoos, & Lammes, 1995). Either way, this lack of understanding is generally attributed to a failure of adequate communication between healthcare professionals and their patients (Murphy et al., 2004).

The deficiency in knowledge displayed by participant couples indicates that they had not actually given informed consent for ART procedures. This deficiency is

best represented by Anna when she says '*And that's a pretty strange thing, because all of a sudden there's people looking inside you and they stuck you in stirrups and all these things'd happen. Plus you have really no idea what it is that they're going to do to you.*' This finding resonates with literature by Braddock, Edwards, Hasenberg, Laidley, and Levinson (1999) who found that informed decision-making was absent in the majority of patient–physician encounters of any kind. This deficit in informed decision making may in part explain the inability of participants of this research to recall details of treatments and procedures they have undergone throughout their time on ART programs.

Daar (2001) refers to the practice of informed consent as being reproductive medicine's most vulnerable feature, and research by Gurmankin (2001) points out that ART programs do not always provide information regarding possible adverse effects of treatment. Pleat, Dunkin, Davies, Ripley, and Tyler (2004) reveal divergent ideas among surgeons regarding how frequently a major risk occurs prior to it having to be conveyed to a patient during the consent process. However, the NHMRC (2004) states, 'Doctors should give information about the risks of any intervention, especially those that are likely to influence the patient's decision' (p. 11). As Reame (1999) points out, a signature on a consent form does not equate to a patient giving informed consent but that the intention should be to give the patient sufficient information to enable them to make well-informed decisions regarding their care, incorporating both risks and benefits of treatment. Whilst it could be argued that couples may not be deterred by some risks, life-threatening conditions (such as ovarian hyperstimulation syndrome) or significant life-altering complications as described in Anna's story may possibly be avoided if couples were aware of the facts. However, Reame (1999) also highlights the

point that the yearning for a child may contribute to patients foregoing their rights regarding informed consent. Couples may not have been concerned about what was happening to them at the time due to their faith that ART would provide them with a much wanted child.

Daar (2001) further highlights the possibility of a conflict of interest if an egg donor is treated by the same physician as the couple attempting to conceive, suggesting that the couple usually finance all procedures involved so the physician would more than likely favour them over the donor. Daar (2001) also states that the physician does not perceive any benefit in the outcome for the donor whereas the couple may 'achieve' a pregnancy, thereby contributing to the success rate of the clinic. With the lack of support shown to Anna and Derek, who may have added to the clinic's success rates, it is not surprising that support for Beth was not forthcoming from the ART clinic. Beth may have been told of some risks associated with the procedure, but risks such as those that became apparent after the amniocentesis were not discussed.

Beery and Shooner (2004) advocate the collection of a family history in order to identify a genetic disease or disorder. In the case of Anna and Beth, a family history would have revealed multiple miscarriages of unknown cause on their maternal side, thereby possibly alerting ART staff to a possible genetic disorder. Nisker and Gore-Langton (1995) affirm that genetic diagnosis of embryos prior to their implantation may avoid terminations in later pregnancy, thus reinforcing the belief held by Anna that such timely genetic testing employed in her case might have ensured a much less devastating outcome. However, genetic testing requires consideration of the impact that certain information will potentially have on those tested. Finding out that the family line is flawed with a genetic abnormality has

significant implications for not just the couple but all potentially affected family members. Whilst Anna's story may not be common, the possibility of such an experience needs to be considered by ART services as a possible adverse event of treatment.

Shanner and Nisker (2001) stress that the exaggeration of success rates often conceals failure rates, and regard this as working contrary to informed consent. Falsely elevated success levels used to market particular ART clinics ensure that greater hope is invested in treatment by the couple. This may also lead to greater risk taking regarding procedures by the couple who are under the impression that their chance of success by delivering a take home baby is higher than it really is.

Limitations of the study

Couples who have been successful in taking home a baby with ART assistance may represent ART services in a more favourable light. Furthermore, as this participant group experienced many of the complicated problems and pathways through ART their point of view may be more jaundiced. On average these couples accessed ART for approximately nine years with a collective experience of 47 years, and therefore they may tell a different story to couples who undertake ART for shorter periods of time. Approximately half of the participants had attended an infertility support group or had formal independent counselling after their decision to cease treatment. Therefore, these participants may have worked through various issues concerning their experiences of ART and childlessness, and now have different concerns from those who have not had access to these types of support.

I acknowledge that infertility and childlessness may hold different meanings and consequences in varying cultures. However, this study included English-speaking couples only in order to promote understanding of participants' stories and to ensure that key aspects of their stories were not lost in translation by a third party.

Although men and women shared their stories independent of the presence of their spouses, it is possible that couples may have a collective story as they have had time to think about ART and its impact on their lives and the decision not to persevere with having children. These couples are close-knit and each spouse relies heavily on the other for support whilst being generally isolated from other social networks. This may create an acute awareness in couples of their spouse's story. Therefore stories told in conversations may be influenced by spouses' experiences and couples may in part have mutually constructed the stories that are presented in this thesis.

Further research

This thesis has explored the experiences of couples who have made the decision to cease accessing ART and remain childless. As other sequelae of infertility and failed ART are reportedly relationship breakdown resulting in separation and divorce (McNaughton-Cassill et al., 2000), further research is warranted within divorced and separated groups who have unsuccessfully accessed ART. Furthermore, the current study has illuminated the need for future research surrounding resilience in infertile childless individuals and couples to determine factors that may assist this population in their transition to a different life path.

This research has also raised questions regarding the impact on those who provide donor gametes for couples and individuals attempting to gain a child via ART. Of

particular concern are issues surrounding information provided to the donor and follow-up care provided, whether the cycle has resulted in a pregnancy, a child or neither. Also, how undergoing long-term invasive procedures effects people is an issue that requires further investigation, particularly with regard to patient education and support and current consent practices for these procedures. Further research that reveals how deeply people invest in these technologies and the underlying reasons for their investment would be worthwhile.

The current study was limited to English-speaking couples. I acknowledged that different cultures place varying degrees of importance on couples' abilities to procreate. A similar study using participants with culturally diverse backgrounds may provide health care professionals with added knowledge to enable them to deliver culturally sensitive care.

The impact of negative language on infertile childless couples is something that has not been widely addressed. As much of the language associated with infertility and childlessness has negative connotations, further research that illuminates how this language affects infertile individuals and couples is warranted.

Recent research

Prior to the commencement of this work, literature concerning ART failure was very much centred on women. Since beginning the current research, a similar study taking into consideration couples' experiences of IVF failure has been completed by Throsby (2004) who analysed interviews using discourse analysis. Although Throsby's (2004) study contributes greatly to a growing body of literature, it differs from the current research in the following ways. Participants

in the current study were interviewed individually whereas couples in Throsby's research were interviewed together. Whilst supporting some findings of the current research, interviewing men with their partners present may have restricted what men said, by Throsby's own admission. Significant differences were found between what men divulged in both pieces of research. Most notable was the way in which men in Throsby's study viewed IVF as a 'natural' technology that was simply assisting nature. This provides a stark contrast to the view of the men who participated in the current study, who regarded IVF as an unnatural and destructive process. Furthermore, some participants in the study carried out by Throsby (2004) were not childless, which may have contributed to different findings. It is difficult to ascertain which participants had children due to the author's consideration for the participants' privacy.

Conclusion

Participants have illustrated through their stories how people are enrolled in the ideal to procreate and the depth and breadth of structural issues that ensure this enrolment. It is proposed that although involuntary childlessness is undoubtedly a distressing and difficult experience for couples, the experience may be exacerbated by false hope and idle promises of a 'cure' by ART services. Infertile individuals and couples would benefit greatly from gaining accurate information regarding their realistic chances of having a baby they can take home. Misleading information given by ART services serves only to delay, for some couples, the inevitable future of living without a biological child. Giving infertile couples hope without providing all options available to them severely limits their life choices and potentially deprives them of time where alternative paths for their future may be pursued, such as other parenting options or careers. This said, however, whilst

participant couples experienced adversity, they showed resilience in the way they were able to work through the complexities of not conforming to the normal narrative of having children.

Appendix 1

Couples who have been unable to have children



Have you had infertility treatment without the desired outcome of children?

Couples who have not become parents after stopping infertility treatment are sought to participate in a PhD research project. Through personal experience, I know that remaining involuntarily childless after infertility treatment involves significant changes for couples in all aspects of their lives.

I am seeking to interview couples who are willing to share their experiences of remaining permanently and involuntarily childless and the impact that this has on their lives.

It is hoped that your experiences can add to the knowledge and understanding of nurses and other health professionals, and enhance their practice in caring for couples ending infertility treatment.

All information will be managed in strictest confidence.

If you wish to participate in this study or simply require more information, please contact

Kath Peters on 0413 288 552 or 9822 9742

Monday-Saturday from 9am-8pm

email: k.peters@uws.edu.au

2073548d 13/8 FAG

Appendix 2



THE FLINDERS UNIVERSITY ADELAIDE AUSTRALIA

GPO Box 2100
Adelaide SA 5001
Australia

**Faculty of Health Sciences
School of Nursing & Midwifery**

Telephone: (08) 82015353
Fax: (08) 82761602
Email: Trudy.Rudge@flinders.edu.au

Dear

This letter is to introduce Kathleen Peters who is a PhD student in the School of Nursing and Midwifery at Flinders University. She will produce her student card, which carries a photograph, as proof of identity.

She is undertaking research leading to the production of a thesis and/or other publications on the subject of what it's like to be childless after trying to become parents using medical treatment.

She would be most grateful if you would volunteer to spare the time to assist in this project, by granting an interview, which touches on events leading up to you stopping medical treatment, what impact remaining childless has on your life and your identity, and what it means for you not to be a parent. Of particular interest to her will be whether men and women experience this process differently. No more than two hours on one occasion would be required.

Be assured that any information you provide will be treated in the strictest confidence and none of the participants will be individually identifiable in the resulting thesis, report or other publications. All names will be changed and all identifying features will be distorted to conceal your identity. However, it is possible that your partner may be able to recognise you from your stories if they read material published from this study. You are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions.

Since she intends to make a tape recording of the interview, Kath will seek your consent, on the attached form, to record the interview, to use the recording or a transcription in preparing the thesis, report or other publications, on condition that your name or identity is not revealed. It will be necessary to make the recording available to professional transcriber for transcription, in which case you may be assured that such persons will be advised of the requirement that your name or identity not be revealed and that the confidentiality of the material is respected and maintained.

Any queries you may have concerning this project should be directed to me at the address given above or by telephone on (08) 8201 5353, fax (08) 82761602 or e-mail Trudy.Rudge@flinders.edu.au

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee. The Secretary of this Committee can be contacted on (08) 8201-3513, fax (08) 8201-3756, e-mail Lesley.Wyndram@flinders.edu.au.

Thank you for your attention and assistance.

Yours sincerely,
Dr Trudy Rudge RN RMHN BA(Hons), PhD.

Appendix 3

INFORMATION FOR PARTICIPANTS

The experience of non-parenthood following infertility treatment failure: Are men and women different?

WHAT IS THE AIM OF THIS RESEARCH?

The aim of this research is to explore what it is like for both partners in a couple to not become parents after accessing assisted reproductive treatment. The study will focus on the individual experiences of both partners in order to establish whether the experience of not having children after accessing infertility treatment is different for men and women. This research aims to increase knowledge and understanding for nurses and other health care professionals involved in the care of involuntarily childless people by highlighting the stories of those who have experienced this. It is hoped that this knowledge will lead to more sensitive care and specific support services becoming available to assist couples in coping with any hardships they may encounter.

WHO IS DOING THIS RESEARCH AND WHY?

I am conducting this study to meet the requirements of a PhD. My interest in this topic stems from my own experiences of involuntary childlessness and the desire to promote understanding of issues surrounding this phenomenon. This research will be conducted under the supervision of Dr Trudy Rudge (Flinders University, Adelaide) who may be contacted on 08 8201 5353, and Dr Debra Jackson (UWS, Parramatta).

WHO CAN PARTICIPATE IN THIS STUDY?

I am hoping to make contact with married couples who have been through infertility treatment and remain permanently childless. If you are willing to share your experiences and have no children (including biological, adopted or from a previous relationship), and if you are able to speak and understand English, I would appreciate your consideration to participate in the study.

HOW DO I PARTICIPATE?

If you are interested in participating in this study, I will answer any questions you may have. If after my explanation you are willing to participate, you will be required to sign a consent form. The consent form states that you are a willing participant and have been given adequate information regarding your participation in the study. It is essential that you understand what is required of you and your rights to withdraw from the study at any time.

After signing the consent form you will be requested to undergo an informal interview, at a time and location that is mutually convenient. The interview could take place in your own home if this is convenient. The only people present at this interview will be yourself and the researcher. I would prefer that your partner is not present when you are being interviewed so that you have the opportunity to tell your individual stories freely and without distraction. At this interview you will be asked to talk about your individual feelings and experiences about remaining childless after treatment for infertility (See attached for the types of questions you will be asked).

The interview will be between one and two hours in length and will be audio-taped. You may at any time request that the taping be paused or stopped and/or that sections of the interview be deleted from the tape.

WILL I BENEFIT FROM PARTICIPATING IN THIS STUDY?

Some people find it beneficial, even helpful to talk about their experiences to an interested party. Other benefits will hopefully become apparent after completion of the study, with nurses and other health care professionals delivering more sensitive and appropriate care.

It is possible that you may experience some emotional discomfort whilst recounting your experiences. In the event that you feel that you require further support, details of a counsellor who specialises in the area of infertility and childlessness and a support group that you may wish to contact, is attached to the information sheet. There will be no financial benefit or cost to you should you choose to participate.

WHO WILL KNOW IF I CHOOSE TO PARTICIPATE?

If your partner is also involved in the study, or if you choose to tell your partner of your involvement, your partner will know of your participation, but whatever you disclose in the interview will not be revealed to him/her. It is possible however that your partner may be able to identify you by your story. You will have full control over what questions you answer and what you say in the interview. You may at any time retract statements or withdraw from the study or only share what you are happy with revealing to your partner. You will be offered a copy of the audio taped interview, or a hard copy of the transcript if you prefer, to review so that you can make sure that you are happy for the researcher to use any or all information for publication. Although others will examine information disclosed by you in the interview your identity would remain anonymous to all but the researcher. Your anonymity will be assured by name changes in any presentation or publication of the information collected. Your personal details and audiotapes will be kept in a secure location within the division of the Faculty of Health Sciences at Flinders University, Adelaide. Transcripts will be stored on diskette protected by a password with the researcher having the only access. These and any hardcopies of transcripts will be destroyed on completion of the project.

WHAT IF I CHANGE MY MIND ABOUT PARTICIPATING IN THIS RESEARCH?

As a participant, you may refuse to answer any question, terminate the interview and/or withdraw from the study at any time without having to provide an explanation. At the end of the interview you may also retract any statement you have made during the interview process. You will also be offered a copy of the tape recorded interview to review and may retract any or all information you have shared form the study at any time prior to completion of the project.

CONTACT DETAILS

Please do not hesitate to contact me with any questions regarding this study

Kath Peters

Ph: (02) 98227742

Mobile: 0413 288552

Email: snk@bigpond.net.au or k.peters@uws.edu.au

Appendix 4

Proposed questions.

Initially you will be asked to tell your story about infertility treatment, events leading up to treatment cessation and remaining childless. If you require further prompting to tell your story you may be asked questions similar to the following:

Can you describe what being childless means to you?

Can you remember the events leading up to when you stopped infertility treatment?

How did you feel at the time you realised you were going to remain permanently childless?

Had you been informed that remaining childless may be the outcome of your treatment?

Did you receive counselling during treatment?

What information were you given regarding the outcomes of treatment?

How did you picture your life prior to this realisation?

How do you picture your life now?

What impact has remaining childless had on your personal relationship(s)?

What effect does remaining childless have on you socially/professionally/economically?

Can you describe how not being a parent effects you emotionally?

Can you tell me about reactions you get from family/friends/colleagues/acquaintances?

How do you think the decision to remain childless will impact on the rest of your life?

What does it mean for you not to be a parent?

What impact does not being a parent have on your identity?

Appendix 5

Professional Counselling Services

Miranda Montrone
Counselling Place
25 Mansfield St,
Glebe, NSW, 2037
Telephone/Fax: (02) 95188615
Email: Miranda@counsellingplace.com.au

Christine Singleton
Sydney IVF
Level 11, 4 O'Connell Street,
Sydney, NSW, 2000
Telephone: (02) 92296488
Email: counsellors@sivf.com.au

Support Group

ACCESS, Australia's National Infertility Network has established an 'Options for Approaching Life without Children' support group.

Initial contact may be made by phoning 1800 888 896 and leaving your details, or alternatively

Email: options@access.org.au

Appendix 6

CONSENT FORM FOR INTERVIEW

I

being over the age of 18 years hereby consent to participate as requested in the tape recorded interview for the research project on couples experiences of childlessness after the cessation of infertility treatment.

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to my information and participation being recorded on tape.
4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
5. I understand that:
 - I may not directly benefit from taking part in this research.
 - I am free to withdraw from the project at any time and am free to decline to answer particular questions.
 - While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
 - I may ask that the recording be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.
6. I agree/do not agree* to the tape/transcript* being made available to other researchers who are not members of this research team, but who are judged by the research team to be doing related research, on condition that my identity is not revealed. * *delete as appropriate*
7. I have had the opportunity to discuss taking part in this research with a family member or friend.

Participant's signature.....Date.....

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's signature.....Date.....

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