The experiences and support needs of non-metropolitan women who have used assisted reproduction clinics.

Karen Bell.

Bachelor of Arts (La Trobe University)

Bachelor of Social Work (Honours grades) (University of Melbourne)

Thesis submitted to *Charles Sturt University* for the Doctor of Philosophy Degree.

December 2009.

TABLE OF CONTENTS

List of tables

Certificate of authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person nor material which to a substantial extent has been accepted for the award of any other degree or diploma at Charles Sturt University or any other educational institution, except where due acknowledgment is made in the thesis. Any contribution made to the research by colleagues with whom I have worked at Charles Sturt University or elsewhere during my candidature is fully acknowledged.

I agree that this thesis be accessible for the purpose of study and research in accordance with the normal conditions established by the Executive Director, Library Services or nominee, for the care, loan and reproduction of theses.

Acknowledgements

Publications

Parts of the literature review have been published:

Bell, K. (2006). An overview of assisted reproduction in Australia and directions for social research. *Australian Journal of Emerging Technologies and Society: 4 (1).*

Bell, K. (2004). Assisted reproduction and the wellbeing of women: Questioning the miracle. *Wellbeing of Women Conference Proceedings.* Charles Sturt University.

Ethics Approval

Approval Number – 2003/050

Charles Sturt University's Ethics in Human Research Committee has approved this project. If you have any complaints or reservations about the ethical conduct of this project, you may contact the Committee through the Executive Officer:

The Executive Officer, Ethics in Human Research Committee

The Grange, Charles Sturt University, Bathurst NSW 2795

Tel: (02) 6338 4628, Fax: (02) 6338 4194

Professional editorial assistance

With the permission of my Principal Supervisor, the services of a professional editor were used to proof read and format the final draft of this thesis (details below). This assistance did not in any way alter or improve the substantive content or conceptual organisation of material.

Dr Bronte J. Somerset

Thesis Formatting and Proofreading (ABN: 96678489321)

5-7 Cobargo Street, Quaama, NSW. 2550.

http://www.mythesis.com.au/

topthesis@gmail.com

Telephone: (61) 2 6493 8112

Abstract

This thesis explores the experiences and support needs of non-metropolitan Australian women in relation to assisted reproduction. It is argued that women's experiential knowledge has not been adequately validated and that a more inclusive knowledge base is required to improve the quality of care in this context. Service providers have much to gain from service users and there are real opportunities for improved service delivery.

 The literature review explores the range of creative possibilities presented by assisted reproduction and how it has captured public imagination since the world's first IVF baby was born in 1978. The wide ranging impacts of assisted reproduction on human society in terms of its medical, legal, ethical and social ramifications are presented.

However, despite these possibilities and collective concerns, it is argued that the dominant paradigm in assisted reproduction remains quite traditional, conservative, biomedical and individualistic in its ontological orientation. Sustained feminist critique has established that women's experiential knowledge of reproductive technology remains largely outside of the dominant paradigm and women in particular are not afforded adequate epistemic agency. The nature of the dominant discourse impacts on regulatory systems, data collection, reporting and on service provision with biomedicine having a disproportionate influence.

Assisted reproductive services in Australia are mainly delivered via privately owned clinics and most of these are based in large metropolitan centres. Some of these primary service providers also deliver services into non-metropolitan areas via outreach, or satellite clinics and a few larger regional towns have their own primary clinic.

This qualitative project focuses on the experiences and support needs of women living in non-metropolitan areas. In addition to general locational disadvantages these women often experience additional, specific service delivery issues and their voices have been particularly quiet in the discourse of assisted reproduction.

The women who participated in this research provide rich information about their experiences of involuntary childlessness and their use of reproductive technology. The adequacy of information and prior knowledge of reproductive technology is described along with their initial expectations about the likelihood of success. Experiences of clinical procedures and evaluations of the quality of care are presented. The various impacts of reproductive technology are discussed along with support needs and sources of support.

Regardless of whether participants reflected positively or negatively on their experiences overall, the overarching theme emerging from their stories is that assisted conception services must be delivered with respect for the privacy, dignity, self-determination and human worth of service users, their partners and families. A human rights approach to service delivery is thereby indicated and the need for consistent, ongoing, multidisciplinary psychosocial support is reinforced.

A major outcome of this study is its contribution to post-conventional knowledge in assisted reproduction and to adequate theory-building in relation to human reproduction based on women's epistemic agency. A unique contribution is also made in terms of the validation of the experiential knowledge of women living in regional and rural Australia.

List of terminology and abbreviations*

AI – artificial insemination, using partner's sperm or donor sperm

AIHW – Australian Institute of Health and Welfare

ANZARD – Australia and New Zealand Assisted Reproduction Database

ANZICA – Australia and New Zealand Infertility Counselling Association

AR – assisted reproduction

ART – assisted reproduction technology

ARTRC – Australian Reproductive Technologies Review Committee

Donor gametes – ova or sperm donated by others to AR service-users for the purposes of assisted conception

FSA – Fertility Society of Australia

GIFT – gamete intrafallopian transfer – after artificial stimulation of ovulation, ova removed via laparoscopy or transvaginal ultrasound aspiration, mixed with sperm and transferred into the fallopian tubes where fertilisation may take place

Hyperstimulation – chemical stimulation of the ovaries to promote multiple oocyte development

Hyperstimulation syndrome – reaction to drugs used to hyperstimulate the ovaries; symptoms may include ovarian swelling, abdominal bloating, weight gain, cardiovascular, pulmonary and electrolyte disturbances. May require hospitalisation if severe, some documented cases have been fatal

ICSI – intracytoplasmic sperm injection – microimplantation of a single sperm directly into an ovum to achieve fertilisation

Insemination – relatively simple procedure whereby sperm are placed in a woman's uterus or cervix via a syringe to achieve conception

IVF – in vitro fertilisation – ova surgically removed from a woman's ovaries and combined with sperm to achieve fertilisation; conceptus left to divide for several days in laboratory environment before resulting embryos are transferred to the uterus of a woman

Laparoscopy – surgery whereby a laparoscope is inserted into the abdomen via a cut near the navel so that a visual image of internal organs is created, used for diagnosis and/or corrective surgical purposes

Motility – percentage of all moving sperm in a semen sample

NHMRC – National Health and Medical Research Council

NPSU – National Perinatal Statistics Unit

OHSS – ovarian hyperstimulation syndrome

Oocyte – ovum, egg

PBS – Pharmaceutical Benefits Scheme

PGD – preimplantation genetic diagnosis – genetic screening of embryos for sex and/or genetic anomalies prior to embryo transfer

Polycystic ovarian disease – a condition where ovaries contain cystic follicles associated anovulation, hormone imbalance, irregular or absent menstruation, sometimes obesity and excessive body hair

Primary (or parent) clinic – Stand-alone, full-time clinic offering range of reproductive technology services

RTAC – Reproductive Technology Accreditation Committee (and part of the FSA)

Satellite clinic – Clinic providing outreach services under the auspices of a primary (parent) clinic, usually to areas without a primary clinic. Usually provide an intermittent clinical service, 3 – 4 times per year.

Sperm washing – laboratory technique to separate sperm from seminal fluid

Surrogacy – gestation of a baby for the purpose of relinquishing the baby to a third party to redress the third party's involuntary childlessness. The baby may or may not be genetically related to the surrogate; gestational surrogacy (embryo genetically unrelated to surrogate mother) / conventional surrogacy (surrogate mother inseminated using 'adoptive' father's sperm or donor sperm).

* based on Wang et.al (2008), ARTRC (2008) and Thompson (2005).

Chapter 1 - Introduction

What are the experiences and support needs of non-metropolitan Australian women in relation to assisted reproduction? This question is central to this study. To adequately explore the research question, consideration is also given to how different service delivery models and the local context of regional clinics might impact on service users' experiences. Overall, it is argued that the dominant biomedical paradigm in assisted reproduction (AR) does not adequately account for the experiences of many women who use these clinics.

For a woman who wants a child but for whom natural conception is challenging, the options are: to accept childlessness; pursue adoption or substitute care; persist without medical input and hope that natural conception eventually occurs; or seek help from the medical profession. If the latter option is pursued and if assisted reproductive services are recommended as the best option to achieve a pregnancy, a range of issues then come into play: what is the likelihood of success and how long might it take before the birth of a healthy baby could reasonably be expected? What sorts of procedures are available and what do they involve? Are there health risks? What about the emotional impacts? How will the use of these services be financed? How much time off work might be needed? Are there waiting lists? Where is the nearest clinic?

Many of these issues are magnified if the nearest clinic is a considerable distance away due to travel, accommodation and opportunity costs. If there is only one clinic within accessible distance, then service-users' choices become limited to that clinic and the range of services it offers. Clients' motivations to seek assisted conception and cultural expectations about motherhood, coupled with access difficulties, result in the creation of a client group with particular needs. This research explores these needs and this context of service delivery by seeking information from women who have experiential knowledge of these issues.

As a project with poststructural, interpretive, feminist intent, it is important to establish some sense of my context or foregrounding (Conroy 2003). This reveals my historicity in the Heideggerian sense of how my past, present and possible future is

intertwined with this project. Sprague (2005, p.168) also urges researchers to describe their own standpoint and reasons for being interested in a particular topic. She notes that this is especially relevant 'within face-to-face research contexts' where the research participants' reactions to the researcher will be important. So, I offer the following account in relation to this project.

First, I have always been a feminist even before the word was known to me. I was born and raised in a rural area and spent the first eighteen years of my life on my family's grazing property on the picturesque slopes of the Snowy Mountains in south-west New South Wales, Australia. My university years were spent in metropolitan locations and after several years of city living, I returned to country life in New South Wales with my partner. Together we have four adolescent sons.

As a girl I always had a keen sense of indignation in relation to gender discrimination. I recall as an adolescent arguing with one of my older brothers about equality between females and males. He argued that males were always going to be physically stronger and therefore dominant over females. I argued that it depended on what was valued in society; that if other qualities were more highly valued, then females' roles and qualities would also be more valued and equality would result. It was not until much later in my first sociology subject at university that the ideas of Juliet Mitchell gave form to my adolescent theory.

All my life I have wanted to be a mother. I was one of those little girls who, along with playing outdoors and with toy cars, spent many hours of play time caring for my two dolly daughters, Melina and Rosebud. An important element of how I envisaged myself in adulthood always involved motherhood. I enthusiastically became a mother in my mid 20s and can only imagine what it is like for women to want motherhood but not to be able to become a mother. As a woman now in her mid 40s, I reflect on how I might have felt had my plans for parenthood not been realised and I am convinced that I would have doggedly pursued the possibilities offered by assisted conception services in the hope of having a child. I can *empathise* with the distress of that situation although I cannot *know* what it is like. It should also be noted that I firmly believe that all people have a range of choices available to them in relation to choosing or not

choosing parenthood and that society should accept a range of roles for women and men in general. So while I have always been keen on parenthood for myself, I do not by any means prescribe this desire as necessary for all.

So my way 'of being in the world' has long been characterised by a desire for motherhood, as well as a critical approach to dominant cultural values and a corresponding disbelief in 'the view from nowhere' (Haraway 1991). As a result of my particular interest in gender issues and because human reproduction is a site of clear distinction between females and males, reproduction has always been an aspect of existence that I find fascinating. So with the advent of assisted reproductive technologies in the late 1970s, my interest was further piqued by the possibilities that these new technologies offered. On first impressions, the technology appears to be, because it is often presented to be, a cure-all for people who are involuntarily childless. But as the longitudinal data on success rates demonstrates, success is limited. And despite the creative potential for the technologies to transform the range of reproductive possibilities, AR for the most part, seems to be enacted in ways that maintain a conservative *status quo*.

Thus the field of assisted reproduction raises some tantalising issues for me and evidently others. Many have explored the implications of the technology over the last thirty years and as the following literature review demonstrates, it has been a rich source for a range of theorists and commentators. What, then, motivates yet another study exploring assisted conception? There is a dearth of recent qualitative, feminist research about assisted reproduction in Australia and very limited research specifically on the non-metropolitan context of service delivery. This research explores how narrow, exclusive knowledge bases are inadequate in the context of reproductive health and why a broader more inclusive, permeable epistemology based on a revised notion of subjectivity is crucial to feminism and in particular in the field of AR. AR is argued to be a potent site of gender control offering a correspondingly potent opportunity to re-envision ontology and epistemology.

The structure of this thesis

This introductory chapter also considers the field of assisted reproduction in more detail and asks what exactly is 'assisted reproduction', how has it developed and why do some involuntarily childless people choose to use it? A broad definition of assisted reproduction and the concept of 'infertility' are also discussed in this introductory chapter.

The literature review begins in this chapter and continues through Chapters Two, Three and Four. It covers material on infertility and the development of assisted reproductive technology; political and ethical considerations, feminist critique, social research and other critiques of AR. The contested nature of 'infertility' and discourses of AR are explored, including the dominant biomedical discourse and competing discourses from feminist critique. Chapter Two details the development of assisted reproduction services and outlines Australia's regulatory framework. Chapter Three presents the major social and ethical debates about AR and Chapter Four focuses on feminist critique. Gaps and inadequacies in the knowledge base will be identified and motivations for the current research located.

Arising from the literature review chapters, Chapter Five distils the conceptual framework for this study. Chapter Six details the methodology used to operationalise the research aim and the next several chapters (7-12) present and discuss the research participants' lived experiences of assisted reproduction. The concluding chapter (13) considers the policy, practice, research and ethical implications arising from the project.

Before exploring the literature, it is necessary to consider the field of AR in more detail; what exactly is 'assisted reproduction', how has it developed and why do some involuntarily childless people use it?

What is assisted reproduction?

Public interest in AR has remained high since the late 1970s. AR has been developed by agricultural scientists, biologists, physicians, biochemists and gynaecologists. It can be argued that its predominant focus is on biology, rather than the human psychosocial and spiritual experiences of reproduction (Rushing 2000). The dominant discourse of infertility constructs it as a state of biological disease and AR is promoted as, and generally perceived to be, a 'treatment' or solution to infertility (Fisher 1989; Seguin 2001). Given that one in six couples is affected by infertility (FSA 2005), the provision of AR has become a 'major industry in most industrialised countries' and it is underpinned by 'powerful professional and commercial interests' (1999a, p.727). It has become an important, if difficult, option for involuntarily childless women and their partners. Clients invest huge physical, emotional and financial resources into AR in the hope of a positive outcome.

Assisted reproduction can be defined as any manipulation of reproduction, from artificial insemination with partner or donor sperm, to hormonal therapy right through to surgical procedures to assist conception (Reed 2001). It includes all procedures that involve handling ova and sperm 'for the purposes of women becoming pregnant' (Tunick 1999, p.53). AR encompasses a range of interventions including in vitro fertilisation (IVF), gamete intra-fallopian transfer (GIFT) and intra cytoplasmic sperm injection (ICSI) and pharmacological interventions such as ovarian stimulation (Garceau, Henderson, Davis, Petrou, Henderson, McVeigh, Barlow & Davidson 2002). IVF and ICSI are the most commonly used methods in Australia (Wang, Dean, Badgery-Parker & Sullivan 2008). The Australian Reproductive Technologies Review Committee Report (ARTRC 2006, pp. 19-20) used the following definition:

> *Assisted reproductive technology (ART) is the application of laboratory or clinical techniques to gametes and/or embryos for the purposes of reproduction. The term ART has now replaced the term in vitro fertilisation (IVF) as ART refers to a range of techniques and services, i.e. not exclusively IVF, which are performed by specialist medical practitioners to assist people who are having difficulty naturally conceiving and carrying a baby to full term. In practice, this mainly comprises either IVF where eggs and sperm are joined outside the body prior to replacement of the embryo into the uterus, or artificial insemination, where – following laboratory preparation – sperm are placed into the reproductive tract of a woman.*

Terminology - Why Assisted Reproduction (AR) not Assisted Reproductive Technology (ART)?

Throughout this thesis the term assisted reproduction (AR) is used in preference to the usual assisted reproductive technology (ART). This preference is based on a desire to focus on experiential *processes* of reproduction via assisted conception rather than focus on the *technology* of assisted conception itself. The habitual use of ART can be seen as a discursive device that serves to emphasise biotechnology and to de-emphasise the social context of reproduction; assisted reproduction depends on more than technology as humans are still required for a successful outcome. The technology is not independent, it is not neutral nor is it autonomous.

Other terminology that reinforces the medical model and/or that disempowers, silences or otherwise obscures the human side of AR will also be avoided as much as possible in this thesis. For example, people will not be 'patients', AR procedures will not be referred to as 'treatments'. Likewise, careful terminology will be used when referring to people who are involuntarily childless; not all involuntarily childless people are 'infertile' and fertility appears to be a continuum rather than a definitive state.

The conceptualisation of infertility

Many people who experience 'infertility' choose to use reproductive technology in the hope of achieving a successful pregnancy culminating in the birth of a child. The definition of `infertility' is, however, contested. The definition of infertility most often used by the general public and by AR service providers regards infertility as the inability to achieve a pregnancy over a one-year period, via sexual intercourse despite regular attempts (Daniluk 2001; Reed 2001). According to Palmer (2004) most people (85%) naturally achieve a pregnancy via sexual intercourse after one year, with 8-15% not achieving a pregnancy within the first year. However, after two years, 94% of people naturally achieve a pregnancy, with the overall average 'trying time' being four months. Similarly, the Australian Reproductive Technologies Review Committee (ARTRC 2006, p.23) also noted that most people (80%) conceive in six menstrual cycles and that a further 10% conceive within the next six cycles (so 90% within one year) and the remaining 5% will also conceive unassisted within three years leaving 5% of people involuntarily childless after three years of unassisted attempts to achieve pregnancy.

The World Health Organisation's definition of infertility also used a two-year baseline. So on this basis a definition using a two or three year baseline would be more accurate than the usual one-year baseline definition.

If a more accurate definition was to gain wider acceptance, it is likely that in most circumstances, couples would be encouraged to attempt conception unassisted for a longer period of time before seeking medical assessment and before using assisted conception services. Some claim that the use of the one-year timeframe is an illustration of the AR industry being 'aggressively entrepreneurial' (Dickens 2001, p.344).

In terms of medical reasons for infertility, ARTRC (2006, pp. 24-27) identified the major causes of infertility as:

- *male factor* – such as azoospermia (absence of sperm), oligospermia (low sperm count), asthenozoospermia (low sperm motility), teratozoospermia (abnormal sperm), testicular failure/ torsion/ abnormalities/ orchitis/ trauma, hormone abnormalities, genital tract obstruction/ infective occlusion, pituitary/ hypothalamic disorders, exposure to radiation, chemotherapy, vasectomy, spinal cord injury, sperm autoimmunity, endocrine abnormalities, etc;
- *female factor* – such as ovulatory dysfunction, reproductive tract disorders – tubal obstruction, endometriosis, developmental abnormalities of the uterus, fibroids, iatrogenic – post-operative infection/ tissue damage, post-surgical adhesions, pelvic inflammatory disease, chlamydia, sperm-mucus problems/ anti-sperm antibodies, etc;
- combined male and female factors; and,
- unexplained/ undiagnosed.

Estimates vary somewhat as to the aetiology of infertility with male factor infertility accounting for 40-50% of situations, according to some sources (Research Centre for Reproductive Health 2007; Reed 2001). Other sources (e.g. ARTRC 2006, p.24) report a more conservative estimate of male factor-only infertility at 30% of all situations, with female factor-only accounting for 37% of cases, combined factors in 20-25% of cases

and unexplained infertility in 5-15% of cases. Yet in most cultures worldwide infertility is viewed as predominantly a 'woman's problem'. For example, see Dyer, Abrahams, Mokoena and Van Der Spuy's (2004) discussion of infertility in South Africa and Inhorn's (2003a) article on infertility in Egypt. This cultural attribution is also reflected in the realm of assisted reproduction where the 'patient' is the woman, regardless of the aetiology of the infertility. Indeed the definition of fertility used in the latest report from the Australian Institute of Health and Welfare (Wang et al. 2008, p.1) reflects this focus on women's attributes in the conceptualisation of infertility as a clinical problem:

Fertility is defined as the ability of an individual to conceive and bear offspring. Infertility is the state of diminished or impaired capacity to do so. Infertility is not an absolute or irreversible condition, but rather a clinical continuum.

This definition and its focus on female capacities (conception, pregnancy and childbirth) obscures the existence of male factor infertility. This bias is curious given that Wang et al. (2008, p.10) identified that female factor-only infertility accounts for 34.1% of fertility problems while male factor-only infertility accounts for 28.7%, combined (male and female factor) accounts for 15.2% and unexplained infertility accounts for 19.3%. In fact the Research Centre for Reproductive Health at the University of Adelaide described a 'growing concern' about the increase in male factor infertility and they noted that conventional diagnostic measures fail to adequately diagnose male-factor problems in 60% of cases (RCRH 2007, p.14). The data then on infertility do not support such a gender biased definition as the one commonly used and indicates a need for a broader, more accurate and gender inclusive definition of infertility.

Nordqvist (2008) also called for a definition that adequately accounts for lesbian women's experiences of infertility and noted that conventional definitions of infertility especially fail to accommodate the fact that for lesbian women, conception is typically separated from heterosexual intercourse.

Another example of gender bias in relation to infertility comes from the Fertility Society of Australia in a survey they commissioned in 2006 to assess 'the perceptions, attitudes experiences and behaviours of Australian men and women to fertility'. One thousand two hundred women and one thousand two hundred men were surveyed via

telephone by a research and marketing company and asked a range of questions about general reproductive health but questions 'specifically about fertility, medical conditions and treatments were only asked of the women' (Labett 2006, p.1).

However, regardless of how infertility is defined and whatever the underlying assumptions of the definition, there is consensus in the literature that infertility is stigmatising (Blyth & Moore 2001) and that it is 'one of the most upsetting life crises' for most people who experience it, particularly for women (Fekkes et al. 2003; Koonin & Napier 2000). In a survey conducted in Australia in the late 1990s, 50% of women and 15% of men said that the experience of infertility was their most upsetting life experience (NHMRC 1998, p.17). The inability to have a child when that is the preference, for most families represents an 'intergenerational developmental crisis affecting extended family members and family relationships' (Hammer-Burns 1999, p.97). Baker (2003) discussed the social exclusion, guilt and relationship tension often felt by those affected by infertility. Schmidt, Christensen & Holstein (2005, p.1050) also argued that women are more likely to be constantly confronted by involuntary childlessness and that men have more 'pain free zones' at their disposal. Baker (2003) said that the 'exclusion from normal adult life' is more sorely felt by women due to proscribed social roles still prevalent in society and also that men are often reluctant to confide in others about their experiences of infertility, sometimes leading to substance abuse and high stress levels as ways of coping with infertility.

Much of the literature on coping with infertility suggests that women and men generally have different coping patterns in response to infertility and that overall, women are more likely than men to describe infertility as a stressful life event and to report greater levels of emotional distress. Some argue that this higher level of distress results in women using a wider range of coping styles and in being more likely than men to openly seek support from a wider social network (Slade, O'Neill, Simpson & Lashen 2007).

Peterson, Newton, Rosen and Skaggs (2006) used psychometric tools to assess the coping strategies of men and women using IVF in Canada. They found that 'acceptance' as a strategy for coping with infertility was the least preferred strategy for

women and men and that 'accepting responsibility' (self-blame) was more likely to result in distress and also more likely to be a strategy used by women. Their findings indicated that in general women prefer to seek social support to alleviate the stress of infertility. They suggested that men tend to approach infertility as a problem to be solved and that the powerlessness of being unable to solve the problem results in additional distress. Their findings however could be limited by the lack of diversity in their sample especially in that male factor-only infertility was underrepresented in their sample.

Roach-Anleu (1999, p.203) also discussed male and female patterns of coping with infertility. She argued that men perceive infertility as 'disappointing but not devastating' in comparison with women 'so long as it remains assumed that the cause of the problem is the female partner'. To this end, she also said that women sometimes adopt a 'courtesy stigma' to protect their partners when male partners have been diagnosed as infertile. Further, Roach-Anleu argued that infertility is regarded as a deviation from social norms and that the stigma attached to this deviation is particularly potent for women who are much more bound by societal expectations around family and motherhood. Klein (1989b) and Bell (2009) also argued that the dominant social construction of childlessness implies abnormality and deficiency and that this influential cultural value underpins reproductive technologies and serves to feed the AR industry.

Despite any differences in coping patterns between women and men, the body of literature clearly establishes that infertility is a distressing life event and that ideally there should be a range of support options accessible to people experiencing infertility. Campagne (2006, p.1651) advocated for early and concurrent psychosocial support during AR service use. However he approached psychosocial support very much from a medical model view in that he identified the need for psychologists (to the exclusion of other appropriate human service professionals) to engage with AR clients to work on 'cognitive, behavioural or psychodynamic changes'. This leaves clients' social context out of the frame of reference and thereby individualises and pathologises clients' distress. Lechner, Bolman and van Dalen (2007, p.288) also

10

advocated for ongoing psychosocial support and refer to the 'complicated grief' brought about by infertility. Several other studies have also identified a need for similar support because of the social exclusion often experienced by people with fertility issues, guilt, stress and relationship tension of infertility (Baker 2003; Verhaak, Smeenk, Nahuis, Kremer & Braat 2007; Wirtberg, Moller, Hogstrom, Tronstad & Lalos 2007).

According to Peddie, Van Teijlingen and Bhattacharya (2005, p.1944) the 'prevalence of infertility has remained relatively stable since 1965' with public awareness and media coverage having 'increased dramatically' along with the availability of an increased range of medical services, IVF in particular since the late 1970s. Roach-Anleu (1999) also noted that despite the incidence of infertility remaining stable, medical consultations for infertility more than doubled in the United States of America between 1968 and 1984. In Australia, there has also been a steady increase in the use of AR; in 2006 there was a 6% increase in the use of AR from the previous year (Wang et. al 2008, p.43).

 The conceptualisation of infertility as a medical problem has been described as 'ethically contentious' (Dickens 2001, p. 335) as it shifts power to medical science – a domain still characterised by hierarchical, gendered power structures and built on a foundation of knowledge firmly from the modernist tradition. Medico-legal practices and discourse then justify and maintain gender inequalities (Diesfield 1999, p.554) with 'infertile couples ... often ... left out of discussions when medical and legal decisions have been made in relation to IVF' (Carl Wood in Nugent-Smith & Nugent-Smith 1985, p. i). Bateman (2001, p. 321) argued that the immediate aim of AR is the conception of a child and that the ultimate social, ethical and demographic consequences of this aim are beyond 'the usual scope of a physician's professional competence and responsibility' and that the legitimacy of biomedicine's dominance in this domain is therefore open to serious question because more than technical competence is needed because of the broader social ramifications. Shanner (1996, p.132) reinforced this and argued that the inability to procreate is 'much more than a physical phenomena… it challenges self-image and social roles' and has a broader

social context; analysis based purely at the biophysical level is not adequate to capture the impacts of infertility on life plans.

Infertility is not strictly a disease, nor is it always a *medical* problem, nor is it generally life threatening. Even if the outcome of AR is a child, the underlying source(s) of infertility, if they are known, usually remain unaddressed. Women become 'patients' and AR procedures become 'treatments' although AR is neither a cure nor treatment for infertility, though this terminology is quite standard in much of the biomedical discourse of reproductive technology. At best, AR could be described as offering the possibility of redressing childlessness for people who desire a child of their own. It is 'compensation rather than a cure' (Shannon 1988, p.156). AR is a palliative option rather than a curative or therapeutic one (Bateman 2001).

There has been some criticism about the referral of women and their partners to assisted conception services on the basis of 'incomplete diagnostic work-ups' and of a variability in the range and number of diagnostic tests used to assess fertility issues (Balasch 2000, p.2251). Gleicher and Barad (2006, p.1951) argued that 'the most frequent diagnosis is non-diagnosis' and that approximately one third of infertility (in the United Kingdom) is unexplained or undiagnosed. Leger (2007) criticised the often hasty referral to and uptake of reproductive technologies without adequate primary care. She advocated that the first line response to fertility issues should be education for wellness and awareness of fertility patterns, charting of menstrual cycles and improved general health to maximise natural conception before resorting to AR to attempt to redress childlessness. One Australian AR practitioner also identified a lack of basic understanding of fertility and the impacts of lifestyle factors, including diet, substance use and age, on chances of natural conception; Chapman – an AR practitioner - stated that many of his clients seem to perceive AR as a reliable and routine solution to infertility but that 'this is a long way from the truth and they really don't know what they're getting themselves into...and changing of lifestyle ... will have an impact on improving their pregnancy rate' (in Field 2008, p.2).

These substantial issues regarding how infertility and assisted reproduction are commonly perceived indicate a need for careful terminology and for more accurate

definitions of key concepts. Thus the term 'involuntary childlessness' is preferable to 'infertility' due to the fact that many women using AR services are not in fact 'infertile' at all, some have infertile partners, some are in social situations where conventional conception is not possible and some are not definitively infertile due to there being no diagnosable reason for their childlessness; the term 'involuntary childlessness' more accurately captures this range of situations. 'Involuntary childlessness' is also preferable because it implies a broader range of possibilities and roles for women (and men) in society and it largely avoids pronatalism, in that the term recognises that some people make a *voluntary* choice to remain childless, reinforcing this is a legitimate option available to all people. The use of accurate terminology like 'involuntary childlessness' instead of 'infertility' along with resisting medical language to describe AR (e.g. treatment, patient, etc) are important steps in the poststructuralist endeavour to disrupt the dominant discourse and contribute to the re-envisioning of a more accurate, inclusive discourse and knowledge base related to involuntary childlessness and assisted conception.

The aim of this study is to broaden the discourse of AR by exploring non-metropolitan women's experiences of assisted reproduction using a post-structural feminist framework. Further exploration of support needs will add to the professional body of literature on the efficacy and ethical implications of psychosocial support, social work in particular, in this field of practice.

Table 1 represents the broad theoretical orientation and major aims of this study. Discussion of the conceptual framework is in Chapter Five. It is acknowledged that presenting the orientation in this way implies fixity and linearity, however it is intended that the boundaries between each 'cell' are seen as permeable and in flux rather than as fixed and impermeable.

Table 1 Broad conceptual aims of this project

This research aims …	Ontology *Ways of being*	Epistemology *Ways of knowing*	Methodology *Ways of doing*
…to explore	Fluidity , dual subjectivity, Connectedness (Shildrick 1996). Active, self-determining subjectivity	Holistic, lived experience of all 'actors' involved Situated knowledge (Haraway 1997).	Phenomenology Qualitative, interpretive mode
…to resist	Cartesian dualism and traditional binaries like nature/culture. The notion of women as a 'patient', 'ontologically out of order' and as 'faulty' bodies (Braidotti 1991).	Fragmented / tightly controlled spheres of knowledge Medicalised view of reproduction / assisted reproduction Expert 'territorialised knowledge' of biomedicine (Shildrick 1996)	Positivist, quantitative, reductionist, universalist approaches

In summary, infertility is still regarded as a predominantly female issue in society and women, whether or not they actually have diagnosable fertility challenges, are often labelled 'infertile' in general discourse as well as in the biomedical discourse. Women's bodies are the focus in assisted reproduction also regardless of the actual nature of the fertility issue and because AR operates from a biomedical knowledge base, women are therefore 'patients' and are required to adopt 'the sick role' in assisted conception. Because involuntary childlessness is typically experienced as a distressing life event

and because AR is not a wholly reliable technology, the need for adequate psychosocial support in service delivery is apparent.

In addition to these concerns AR is regarded as having a wide range of societal impacts. But before focussing on ethical, legal and policy issues in Chapter Three, the following Chapter (2) provides an overview of the development of AR technology to demonstrate the pace of change and rate of acceptance of these procedures into society. It also considers the regulation, funding, legislative and policy context of AR in Australia along with outcome measurement and reporting issues.

Chapter 2 – An overview of the development of assisted reproduction

The previous chapter established the aims of this research and the researcher's motivations and historicity. The phenomenon of involuntary childlessness was explored and some definitional issues relating to infertility and assisted reproduction were raised. It is now important to get a sense of the broader context of reproductive technology, its development over time and the current state of service provision in Australia including regulation, funding, service delivery networks and outcomes.

Just as involuntary childlessness has long been experienced by some humans, various methods, superstitions and cultural practices aimed at assisting conception have also been of interest to them. The Bible refers to surrogacy and ancient accounts of reproductive creativity and attempts to assist conception in order to redress involuntary childlessness (Blyth and Farrand 2005). There is documented evidence of the use of 'low-impact' technologies such as artificial insemination since the 1970s, by lesbian women (Nordqvist 2008). Braidotti (1994, p. 88) noted that there is a history of 'male fantasies' about the control of reproduction and the first recorded attempt to fertilise mammalian ova outside the female body occurred in 1878 in Vienna when ova from rabbits and guinea pigs were fertilised in-vitro but did not develop (Winston 2007). In 1934, the first mammalian ovum (a rabbit's) was successfully fertilised. In the 1940s, human ova were successfully fertilised *in vitro*, though not transferred into a woman's body (Lorber 1988). With sustained advances in medical science and techniques, the development of AR gained increased momentum in the mid-twentieth century.

The first 'unequivocal mammalian IVF birth' (non-human) occurred in the United States of America in 1959 (Lorber 1988, p.119). The pace of experimentation in reproduction was sustained and in 1973 the first IVF pregnancy, sustained only for one week, occurred in Australia (Wood & Gordon 2001). In 1978, the first human IVF baby, Louise Brown, was born in the United Kingdom (Gooch 2003). Ms Brown's birth reportedly occurred after many years of experimentation by Steptoe and Edwards, including sixty-eight laparoscopies on women and the transfer of embryos to eleven women, most of

which failed to implant and one which resulted in a miscarriage at ten weeks due to foetal abnormality (Fisher 1989, p.261).

The first partially successful IVF procedure in Australia occurred in 1979 and the first Australian (the world's third) IVF baby was born in Melbourne in June 1980 (Wang et al. 2008). Between 1981 and 1984, there were thirteen IVF babies born worldwide, twelve of them born in Australia (Gooch 2003). Since the early 1980s, there has been significant growth in the number of AR clinics in Australia and in regulation and government funding for these clinics. Wood and Gordon (2001) comment that IVF became 'more practicable' in the 1980s, with the advent of ovarian hyperstimulation to produce greater quantities of ova per AR cycle. Australia's pioneering lead in AR means that Australia is regarded as a 'significant player' in the development of the technology as well as the regulation of AR.

The regulation of AR in Australia

Australia 'may be variously described as a rich tapestry of diversity in terms of the regulatory structure or a patchwork of regulatory stitching lacking cohesion and order' (Szoke 2003, p.75). To date, there is still no uniform Federal legislation but a range of state-based legislation exists as well as accreditation guidelines. As early as 1985, calls for national regulation were made to the Australian Family Law Council review stating that because AR raised fundamental social, moral, legal and ethical issues for the whole community that there must be a national, multidisciplinary regulatory body (Fisher 1989).

In 1986 the peak body representing the AR sector – the Fertility Society of Australia (FSA) and its accreditation committee - the Reproductive Technology Accreditation Committee (RTAC) - developed a Code of Practice for AR clinics and this code, along with updates and revisions, is still the benchmark for service providers. This accreditation committee, according to the report of the *Independent Review of Assisted Reproductive Technologies* (ARTRC 2006, p. 51), draws its membership from 'relevant health care providers' – with most coming from the AR sector and with biomedical qualifications. In 2009, out of a membership of sixteen, thirteen have biomedical backgrounds, one is an accountant, one has psychosocial qualifications and

there is one service-user representative (FSA 2009). This could be regarded as evidence of the 'enmeshment of doctors' and closely allied health professionals into the dominant regulatory structures of AR (Bell 2009, p. 693) – the 'culture of biomedicine' (Thompson 2005, p.245) or what Rapp (2004) referred to as keeping the foxes in charge of the hens' coop.

In terms of legislation, the State of Victoria was the first jurisdiction in the world to introduce legislation. In 1982 one of the first of a series of State-based inquiries was undertaken in New South Wales (NSW) and more discussion papers followed in 1984, 1986 and 1988 (Waller 2003). It took until 2007 for NSW to enact its legislation governing AR - the *Assisted Reproductive Technology Bill* 2007. In 2009, in addition to the NSW legislation, the other Australian states with legislation specific to assisted reproduction are Victoria (Assisted Reproductive Treatment Act 2008), Western Australia (Human Reproductive Technology Act 1991 and the Amendment Act 1996) and South Australia (Reproductive Technology Act 1988). The remaining States and Territories refer to the National Health and Medical Research Council's guidelines and recommendations for ethical practice; although the NHMRC may issue these guidelines it does not have the power to enforce them (ARTRC 2006).

Other relevant legislation includes the Queensland legislation regarding surrogacy arrangements (the Surrogate Parenthood Act 1988) and embryo research (Research Involving Human Embryos and Prohibition of Human Cloning Act 2003). The Australian Capital Territory also has legislation relating to surrogacy (the Substitute Parents Act 1994 and the Artificial Conception Act 1985) as does Tasmania (the Surrogacy Contracts Act 1993). Clinics in the Northern Territory (NT) are required to adhere to the South Australian guidelines, with some exceptions which restrict access to NT clinics by non-heterosexual couples and single women (DHS 2004). Across Australia then, there is considerable variation in some aspects of service delivery due to variations in relevant legislative frameworks and consequently variations in equity of access to Federal government funded health procedures.

Australia's legislative and regulatory system remains a 'patchwork' and cannot really be regarded as a rich tapestry with a cohesive form, particularly given the absence of

an effective system of mandatory, independent national accreditation. At the 2003 meeting of the Council of Australian Governments (COAG) there was an indication of Federal and State governments' desire to work towards uniform legislation across Australia to standardise the regulation of AR (FSA 2004) but to date, no advances have been made in this regard. The call for national mandatory regulation and accreditation was repeated in the ARTRC (2006) report in the interests of ensuring uniformity in the collection of information on the clinical effectiveness of AR and in the systematic recording and reporting of adverse outcomes for service users and, importantly, for ante-natal and perinatal tracking and follow-up to ensure that longitudinal information on outcomes was not underreported.

Government funding

In terms of government funding, Australia 'has one of the most generous public funding regimes ... for reproductive technologies in the world' (Smith 2006, p.3) and almost 80% of Australians were said to approve of government funding for AR (Kovacs, Morgan, Wood, Forbes & Howlett 2003, p.536). The Federal government introduced rebates for AR in 1990 via its universal health care system – Medicare - initially with a limit of 6 Medicare-funded cycles. In 2000, the six-cycle limit was removed (Health Insurance Commission 2005). Israel is the only other country with 'uncapped' funding support for AR cycles. The United Kingdom's funding arrangements vary according to location, 'the postcode lottery' (Garceau et al. 2002, p.3091), with Scotland being the most generous in providing funding for three cycles. In the Netherlands, funding is provided for three cycles; New Zealand for two cycles per couple, and Germany and France fund four. In the United States of America, there is no public funding for AR and a proportion of costs may or may not be covered by private health insurers, meaning that most people pay for their own service use (Smith 2006). In Canada, Ontario is the only province providing limited funding for IVF to women with bilateral fallopian tube blockage (Jones, Cohen, Cooke & Kempers 2007).

The level of funding support is said to be strongly related to access to AR and also to continuation of service use; in countries with limited access, there is a corresponding drop-out rate (Rajkhowa, McConnell & Thomas 2006). However, even with uncapped

funding, in Australia, 50% of people stop AR after one failed cycle and 54% stop after four failed cycles (ARTRC 2006). Reasons for discontinuing AR use vary and while they do relate to affordability and accessibility, they also include the psychological burden, poor prognosis, achieving natural pregnancy, physical burden and the advent of other serious disease (Arndt 2005; Olivius, Friden, Borg & Bergh 2004).

Despite the significant amount of Australian government funding for assisted conception services, funding is not linked to service standards or accreditation requirements or evidence of clinical effectiveness. Australia's Pharmaceutical Benefits Scheme (PBS) also covers some of the costs of pharmaceutical products required for AR regimes. The amount of PBS funding has increased steadily over the years and in 2005 amounted to almost $50 million (ARTRC 2006, p.22).

Clients face a range of charges not only for AR procedures but also for other associated costs like anaesthetist fees, day admission to medical facilities, biopsies, pathology, post-treatment medication, administration charges, etcetera (for examples see MIVF 2004). 'Out of pocket' or 'gap' costs per IVF cycle were at least $1500 in the early 2000s even after the Medicare rebate (Sinclair 2003, p. 4) and up to $3000 per cycle (Wroe 2005). Given that many couples use AR for several cycles, the total cost is likely to be substantial. In addition to these identifiable costs, the hidden costs of pregnancy monitoring, childbirth interventions, pre-term births and subsequent care, treatment for iatrogenic damage, disability support, research grants, etcetera, must also be recognised (Ewing 1992; Garceau et al. 2002).

 In 2004, the Extended Medicare Safety Net was introduced as a way to offset some of these out-of-pocket costs. This safety net means that once a certain threshold amount in 'gap' costs is reached, consumers are able to claim 80% reimbursement of the those costs. So AR service users are covered by a two-stage Medicare rebate system for an unlimited number of cycles.

In 2005 there was some debate about whether Medicare coverage for AR procedures should be limited to three cycles per year for women under the age of forty-two years, and to three cycles in total for women over forty-two (see for example Metherell 2005; Wroe 2005). After lobbying by interest groups, the Government decided to retain the

funding *status quo* and to commission an independent review into the clinical effectiveness and costs of AR - the Assisted Reproductive Technologies Review Committee (ARTRC 2006) review.

The major findings of the ARTRC (2006) review were that:

- the average cost per live birth is just under $33,000, 80% of which is met by government funding;
- in 2003 Medicare expenditure for AR services was $50 million and in 2005 expenditure was $108.4 million – an increase of 117%. If Pharmaceutical Benefits Scheme funding is added to this, the increase is 146% since 2002. ARTRC noted that 'the escalation of government expenditure in this area is bound to continue' in large part, they claim, because of delayed child-bearing;
- consistent national accreditation standards are needed and these should be linked to government funding and clinical effectiveness;
- there is a need for a community education initiative to increase awareness of fertility issues, especially age-related infertility, preventable infertility, multiple birth risks, and alternatives;
- based on existing evidence, that no new AR services be offered to women over the age of 44 years;
- there is a need for ongoing review of new technologies and their effectiveness and possible side-effects, and;
- improvements are needed in data collection, adverse incident reporting and consumer information, including regulation of clinic advertising and success rate measures used in advertising.

The government response to this report was favourable and most recommendations were accepted, including a commitment to expanding funding for ICSI and an update of other Medicare items. The only recommendations effectively dismissed were the public education campaign about fertility preservation and the recommendation for limits to be imposed on access to AR for women over the age of forty-four years (Department of Health and Ageing 2006).

In summary, AR in Australia receives significant funding from the Federal government but lacks a cohesive national system of legislation and regulation and comprehensive data collection.

The expansion of AR clinics

In 2006, there were twenty eight assisted conception providers operating in approximately sixty eight different locations in all states and territories of Australia (Wang et al. 2008). In most industrialised countries it is a 'major industry' underpinned by powerful commercial and professional interests (Blyth 1999a, p.727). Most Australian clinics are based in metropolitan locations (over 75%) and approximately 20% in large regional centres, just under 2% in small regional centres and just under 2% in very small regional centres. Most clinics outside of metropolitan locations were outreach or satellite clinics of primary (parent) clinics based in the larger cities. Primary clinics generally have a range of services and staff on-site, full-time, while satellite/outreach clinics offer some, but not necessarily all AR procedures and support services to clients. These clinics may not be operational full-time; many operate on a regular 3-4 monthly pattern of visits. This cyclic pattern of operation necessitates the synchronisation of menstrual cycles for all women using the service at that time. These inequities in service delivery to rural and remote areas are seen by the industry as inevitable because of the complexity of AR procedures and because the specialist staff required to deliver these services are typically based in larger metropolitan locations (ARTRC 2006). Much of the literature on satellite or 'transport' clinics focuses on the biomedical aspects and economic efficiency and not the psychosocial issues although convenience for service users and community care are given some relatively brief attention (e.g. Brinsden 1999; Qureshi, Walker, Pike & Murray 1997; Roest, Verhoeff, van Lent, Huisman & Zeilmaker 1995).

Assisted reproduction in Australia and internationally is 'big business' and 'is life changing when it works, but it is accompanied more often by failure than success' (Winston 2007, p.9). Williams (2008, p.2) reported on the growth in private equity investment in the sector in recent years. She noted that despite the growth in private investment, most companies are still majority owned by medical practitioners and staff

with shareholder registries dominated by doctors. She argued that the sector is likely to continue growing because 'private equity loves a growth industry...an industry heavily supported by taxpayer funding is even more attractive'. Burfoot (1990, p.72) argued that another spin-off of AR's market success is that commercial interests are 'likely to prevail against a women-centred approach to reproduction'. Despite the economic boom in biotechnology, many practitioners maintain that the focus is on 'the best interests of the patients' (Hale in Williams 2008, p.3). According to Min, Breheny, MacLachlan and Healy (2004) the focus of AR has changed from the clinicians' initial focus on creating pregnancies as a measure of success to the delivery of healthy babies. But how successful and how clinically effective is the technology in this regard? What do service users expect?

Outcomes of AR

The popular perception of AR is that it is in fact a successful cure for infertility and popular opinion, reinforced by media success stories, is often at odds with the statistics and the experiences of many women and their families. Most service users and the general public 'consistently over-estimate the success of reproductive technologies' (Hammer-Burns 1999, p.100; Peddie, Van Teijlingen & Bhattacharya 2005). Public perception appears to remain positive (Kovacs, Morgan, Wood, Forbes & Howlett 2003) and popular media tends to emphasise the successes of AR and reinforce a perception of it as an increasingly routine, viable, unproblematic and successful treatment for infertility. Trounson (1999, p.660) noted that although AR was 'widely condemned by some particular interest groups' that it is 'now well tolerated by the community'.

The tendency for most people to overestimate the likelihood of successful childbirth after AR is the consistent finding of several research projects (Adashi, Cohen, Hamberger, Jones, de Kretser, Lurenfeld, Rosenwaks & Van Steriegem 2000). In an international survey of six European countries plus Australia and the United States of America, it was found that 90% of respondents knew about IVF but less than 25% had an accurate idea of success rates. In a random telephone survey of over 3,000 Australians in 2003-2004 conducted by Qu and Weston (2005) to explore fertility

decision-making, it was found that almost two-thirds of respondents thought that AR would be 'likely' or 'very likely' to be successful; one quarter of respondents were not sure and only 8% thought that success was 'unlikely' or 'very unlikely'.

Given that people access AR clinics after a period of involuntary childlessness in the hopes of achieving pregnancy and of giving birth to a healthy baby, the measurement of success in AR is a major issue. Success as it is sometimes represented in clinic documents and on websites, has been criticised for not clearly and easily relating to these hopes (ARTRC 2006; Daya 2005; Min et al. 2004; NHMRC 1998). Even a cursory sample of some clinics' websites reveals that Australian clinics still state their success rates in various ways. Some still show their success in terms of clinical pregnancies achieved - that is an early positive pregnancy test not necessarily resulting in an ongoing viable pregnancy culminating in the birth of a child; or ongoing pregnancies achieved and not necessarily in terms of healthy, live births achieved per client per treatment cycle started. Thus, it is often unclear as to what a clinic's advertised success rates actually represent. In many instances, clients would need considerable critical skill to evaluate the data presented to them relating to outcomes after AR procedures (ARTRC 2006; Fisher 1989; Klein 1989b; NHMRC 1998).

From 1985 until 2002, data on some of the outcomes of assisted reproduction were collated by the National Perinatal Statistics Unit (NPSU) under the auspices of the FSA. This database was superseded in 2002 by the Australian and New Zealand Assisted Reproduction Database (ANZARD) (Wang et al. 2008). The annual report series *Assisted Reproduction Technology in Australia and New Zealand* aims to provide information on 'treatment cycles and resulting pregnancy outcomes', evidence on 'quality improvement...success rates and perinatal outcomes', information on national and international comparisons to inform standards of practice, monitoring, accreditation and regulation of AR clinics (Wang et al. 2008, p.2). The reporting is largely limited to quantitative data and the authors identify other significant limitations in some data sets such as the data on adverse reactions to ovarian stimulation, pregnancy and birth complications and perinatal outcomes. The authors note that information on these aspects of the AR experience is based on limited, variable and unsystematic follow-up

and on self-reporting, especially of pregnancy complications, complications of AR procedures and infant morbidity (Wang et al. 2008, p.51).

While the importance of reliable quantitative data is undisputed, there is a clear need for a more systematic reporting and data collection regime as well as a need for a wider range of data to be sought about AR. The exclusion of other data, particularly qualitative data on service users' experiences, is a major oversight. The absence of demographic data on service users means that it is difficult to assess access and equity issues in this context and taxpayer-funded health services need to firmly demonstrate that they are safe, accessible and equitable for all citizens.

In light of variations in how success is defined and because likelihood of success is vital information for service users, various authors have recommended that data on AR outcomes be systematically and centrally collected and collated, and that the outcome measure should be communicated in accessible terms to reflect the birth of healthy live singleton babies born per client per treatment cycle started (ARTRC 2006; Klein 1989b; Min, et al. 2004; NHMRC 1998; Purdy 2000; Shannon 1988; Wang et al. 2008).

The ANZARD annual reports do use 'live delivery' as the endpoint measure of success – similar to the 'birth emphasising successful singleton at term' (BESST) endpoint measurement advocated by Min et al. (2004). The BESST measurement takes into account all non-donor treatment cycles started in which ovulation drugs were used and 'defines the successful endpoint as a single, live baby at full gestation of 37 weeks or more' (Bryant, Sullivan & Dean 2004, p.15). In 2006, in approximately 83% of all 'treatment cycles started', clients did not achieve a live birth (Wang et al. 2008) - a figure comparable to international success rates (ARTRC 2006). That is, in 17.3% of all treatment cycles for all age groups, the end result was a live born baby. The rate of success for younger women was better with women 24 years of age or younger giving birth to a live baby in 39.5% of all cases. The birth rate starts to decline after the age of 32 years, and for women aged between 40 and 44 years, the success rate was 9.9% and for women 45 years or older, 1.1% (Wang et al. 2008, pp.14-15). These outcomes

25

clearly do not correspond to public perception and to the belief that AR is 'likely' or 'very likely' to eventuate in a live born child (Qu and Weston 2005).

It is a positive development in national reporting on AR outcomes that success is standardised in this way, but in terms of how individual service providers represent outcomes, the picture is less encouraging. In 2004, the NHMRC issued revised guidelines on the nature of patient information requiring clinics to use plain language to describe the side effects, the legal, financial and psychosocial impacts of procedures and to report on success rates in a clear and accessible manner. However, clinics' marketing material and online reporting of success remains variable. Indeed service providers' websites and media advertising often contain claims of a competitive edge over other clinics in terms of success rates. Without mandatory regulation and standardised advertising requirements, potential and actual service users are left with inconsistent information upon which to compare clinics and make effective consumer choices, if indeed they have any choice in accessible service options. Most non-metropolitan people will have a very limited range of options.

While 'success' in ANZARD reporting is now standardised, the continued variations in the ways individual clinics report success remain a concern. If standardised measures of success were used by all clinics and more information on associated risks was available, this would be more meaningful to clients. It would enhance the decision-making process in relation to AR and would facilitate more realistic expectations about outcomes and risks. In addition to this, it would be useful for clients to have some indication of the average number of treatment cycles undertaken by service users to achieve a successful live birth as well as information on the proportion of clients who discontinue AR without achieving a live birth. This would assist people in their decision-making regarding their use of AR procedures and help service users to set limits on their uptake of AR, as recommended by Peddie et al. (2005). Likewise this breadth of information could inform policy decisions about funding and regulation of AR services.

The success rates of individual clinics, even when reported by ANZARD using a standardised measure also varies considerably. ANZARD reporting also does not identify individual clinics; rather, it aggregates comparative data to demonstrate variation in success across the sector. The most successful clinics (the top 25%) have overall success rates of between 23% and 29%, the bottom quartile have success rates between 2.8% and 15.5%. So the overall variation between clinics in Australia in New Zealand in 2006 was between 2.8% and 29.2%. Service users would no doubt appreciate being able to access reliable information on the quality of their particular service provider and to make informed choices about where to spend their money. Policy decisions would also be better informed with access to more specific information of this nature.

The use of live birth as a measure of success is sensible, but arguably, other measures of success should also be considered so that the *process* of AR is adequately accounted for and not merely the endpoint – the end justifying the means. To this end, researchers in Ireland focused on success as measured by live birth *per ovum retrieved*, and the failure rate of assisted conception was 96.4%. This data corresponds with research in the United States of America where the per-ovum-retrieved success rate was between 1% and 7% (Waite and Harrison 2004). Likewise Inge, Brinsden & Elder (2005, p.588) reported that despite more than two decades of AR implementation, that the 'efficiency of oocyte utilisation has not improved significantly since the early 1980s'. Given the routine use of ovarian hyperstimulation and the impacts of these procedures on women, success per ovum retrieved also makes a great deal of sense from a female's perspective as well as in terms of clinical and technological success.

The persistent representation of AR as a modern miracle, even in the face of data indicating otherwise, reinforces images of science triumphing over nature and the ability of humans to conquer all via technology and 'know how' (Hellwege 1999; Klein 1989a; Murdoch 1985). It appeals to the belief that medicine is a cure-all and that everyone can achieve pregnancy (Djerassi 1999; Gosden 2000; Murdoch 1985; Wiczyk 2000). For example, comments such as the following illustrate this point:

- 'If you want to have a child, you just go on IVF …there's no necessity to be childless now' (Gooch 2003, p.5);

- that reproductive technology is 'fertility insurance to stop the biological clock' (Shenfield and Sureau 2002, p. 6);

- that pregnancy is 'often, but not always' achieved via assisted conception procedures and that success rates 'have zoomed upwards' (Sinclair 2003, pp.1 & 4);

- ovarian tissue can be safely cryo-preserved until 'Mr Right' comes along as a reliable option 'to beat mother nature' (Benson 2008).

This discourse of AR mirrors a shift in the more general discourse of public health from one based on social hygiene concerns to one based on miracle technology with medical practitioners being increasingly seen as 'technologists of the body' rather than as healers of the sick (Webster 2002a, p.451). This discursive shift depends in large part on the technology fitting with existing social relations such as gender roles and relations, pronatalism, on masking any uncertainty about the effectiveness of the 'miracle' and on emphasising a range of claims about the bright future promised by the technology (Seguin 2001; Webster 2002a). Given this tendency to overplay the success and clinical effectiveness of reproductive technology, how are other actual and potential adverse outcomes accounted for?

Adverse outcomes

Research into genetic anomalies, health problems and safety issues for AR babies indicates that there is a significantly increased risk of adverse outcomes for these babies (Hansen, Kurinczuk, Bower & Webb 2002; Kolata 2002; Lambert 2002 & 2003). Pregnancies achieved after assisted conception are more likely to eventuate in various adverse outcomes. For example, there is a higher risk of maternal death (NHMRC 1998), spontaneous abortion, foetal abnormalities and of terminations for foetal abnormality, as well as a greater chance of stillbirth, and a rate of perinatal death 2.5 times higher than naturally conceived pregnancies. Pregnancies achieved via ICSI have the highest rates of termination and 'foetal reduction' when compared to other assisted conception pregnancies. There is a higher chance of pre-term birth (21-33% in

AR babies compared to approximately an 8% chance for naturally conceived babies) and a higher rate of low birth weight for AR babies (26.4% compared to 6.8% in non-AR babies) (AIHW 2003; Wang et al. 2008).

In terms of the childbirth experience after AR, there is a greatly increased chance of medical intervention in childbirth with an overall rate of 50% of babies being born via caesarean section, compared to 23.3% for natural conceptions. Forty-seven percent of singleton AR babies are born by caesarean and 78.5% of AR twins and 86.4% of AR triplets are delivered by caesarean. The rate of multiple pregnancies after assisted conception has been steadily declining in recent years, largely due to changed practices at the embryo transfer stage and the growing trend towards single rather than multiple embryo transfer (Wang et al. 2008) and a growing acceptance that single rather than multiple embryo transfer results in better outcomes in terms of clinical outcomes as well as social and economic factors (Wang, Sullivan, Healy and Black 2009).

Along with increased risks of pre-term birth, operative childbirth and low birth weight, the need for neonatal intensive care and the risk of perinatal mortality are greater for babies born after assisted conception. The higher rate of multiple births in AR is identified as one possible reason for some of these significant differences. Some of this data is from self-reporting of pregnancy, birth and neonatal issues and so the actual incidence of adverse outcomes is likely to be even greater (Wang et al. 2008, pp. 37 & 51). Hammarberg, Fisher and Rowe (2008, p.1567) used telephone interviews and self-report questionnaires for one hundred and sixty six Australian women and likewise found that AR pregnancies often result in 'operative birth' and that this has an influence on 'early post-natal adjustment' for women. This is likely to have broader impacts on early childhood health service delivery and possibly also on rates of postnatal depression and the need for ongoing gynaecological care due to birth complications and interventions. Thus these 'poorer neonatal outcomes' of assisted conception babies and mothers compared with non-AR babies and mothers are 'significant enough to impact healthcare resource consumption' (Chambers, Chapman, Grayson, Shanahan & Sullivan 2007, p. 3108).

Hansen et al. (2002) found that babies born after AR are at least twice as likely (and possibly up to three times more likely) to suffer from abnormalities than naturally conceived babies - in particular abdominal organ abnormalities with ICSI conceptions being at even greater risk than non-ICSI conceptions. Many of these defects do not become apparent until the child begins walking so the researchers advocate longitudinal follow-up of AR children to reliably assess the longer term health risks of the technology. Other research has also identified a need for long term follow-up and has indicated that the major neonatal problems and congenital anomalies faced by AR babies are sex chromosome disorders, imprinting disorders and cerebral palsy (Barlow 2002).

In addition to congenital abnormalities and other defects, Helmerhorst, Perquin, Donker and Keirse (2004) in their meta-analysis of controlled studies on AR outcomes, found that the rate of pre-term birth for AR babies is double that of natural conceptions and that 40% more infants are small for their gestational age compared to non-AR babies. They also found that outcomes for AR twins were somewhat more positive than for naturally conceived twins in terms of perinatal mortality and neo-natal monitoring. Lambert (2003, p.1988) also identified health problems in children born after AR but notes that while the relationship between IVF, ICSI and congenital malformations is 'still controversial' that the relationship between IVF, ICSI and 'other adverse effects ... are largely supported by the literature'. All of these studies advocate for better information on the risks of AR for service users and for a greater focus on narrowing the health gap between AR and non-AR babies. Given that AR has been offered to women and their partners since the late 1970s, the lack of reliable knowledge about the possible health risks is a major deficit.

Winston (in Thomas 2003) asserted that many practitioners minimise the possible risks and adverse outcomes of assisted conception. For example, Kovacs (1996, p.62) stated that the picture is 'reassuring' in terms of outcomes and risks and that there are 'no significant differences' in IVF babies whereas it would seem that a more circumspect, cautious approach to the lack of systematic data would have shown a more accurate reflection of scientific evidence at the time. Winston also noted a tendency in the

industry to dismiss research critical of AR stating that research into the health risks of the technology 'has by and large been dismissed by the medical community' (Winston in Thomas 2003). Chapman, a representative of the FSA, (in Salleh 2008, p. 1) described calls for effective monitoring of IVF outcomes for epigenetic effects as 'provocative' and stated that children are being monitored (he did not elaborate on how) and that 'if something starts to turn up, it will jump out at us'. It is difficult to see how this would occur in the absence of national, systematic, scientifically rigorous longitudinal monitoring and reporting of AR outcomes**.**

Winston (in Thomas 2003) also indicated a lack of scientific knowledge about the effects of the pharmaceuticals given to women to hyper-stimulate ovaries. In addition to the gaps in biomedical knowledge, Brod, Verhaak, Weibinga, Gerris and Hoomar (2009, p.391) argued that there are gaps in experiential knowledge and qualitative information on the impacts of ovarian hyperstimulation on women's quality of life. They advocated the development of a more 'patient-centred approach to treatment'. It should be noted that in most of the literature advocating better longitudinal information or on commentary dismissing the need for effective monitoring of AR, the focus is usually on children born as a result of the technology rather than on the women who have used it. As Thomson, Lind, Roberts, Robertson and Robinson (2002) stated, the scarcity of evidence-based analysis could be due to a combination of factors including complexity, cost and possibly reluctance to critique reproductive technology. But until there is 'sustained long term tracking of the health of children and adults conceived via AR that 'human ART procedures remain a series of experiments in progress' and that this research is of 'paramount importance despite the difficulties involved' (Thomson et al. 2002, p.2788).

In summary, the implementation of human reproductive technology has been quite rapid. Australian scientists were at the forefront of research and experimentation in reproductive technology and many of the pioneering IVF births in the 1980s occurred in Australia. The regulatory framework that quickly developed, while not necessarily cohesive, along with relatively generous government funding support has facilitated the expansion of service delivery networks in this country. Australia's service delivery

network has expanded to a point where there is currently a range of primary clinics, mostly based in metropolitan population centres and satellite clinics, mostly based in non-metropolitan centres. This relatively rapid progress from initial experimentation to implementation and expansion has stimulated considerable commentary from a wide range of fields. The following two chapters explore this commentary, commencing with social and ethical considerations in Chapter Three and moving on to feminist critique in Chapter Four.

Chapter 3 - Social and ethical considerations

The previous chapter described the development of reproductive technology and in particular its implementation in Australia. The nature of regulation, funding and distribution of the service provider network was discussed. The focus now shifts from the broad context of reproductive technology to explore the nature of social, ethical and other commentary in relation to AR.

The development of reproductive technology and its relatively rapid application to humans has provoked strong reactions from various sources, such as bio-ethicists, theologians, service users and feminists. Notwithstanding ARTRC's claim that 'there is a scarcity of literature regarding the social, ethical and legal issues emanating from ART' (2006, p.40), since the 1970s, there has in fact been a sustained and considerable international effort to explore the various ramifications of assisted reproduction. By the early 1990s, there were over one hundred reports published by governments and professional bodies worldwide exploring the ethical, legal and social issues of AR (Blyth and Farrand 2005, p.92). Along with the substantial body of biomedical research and conferences and publications, philosophers, anthropologists, ethicists, feminists, sociologists, social workers, theologians, lawyers, psychologists and others have explored this field, published extensively and it remains a focus for many. The complexity of AR and its melding of science, society and human desire for a child ensure that there are many avenues of enquiry into this field where 'what seems to be at stake is a transformation of the anthropological conditions of procreation' (Bateman 2001, p. 330). AR raises many complex ethical and social issues. The following provides an overview of some key ethical issues as a precursor to the exploration of social research and critique of AR.

Ethical considerations

The bioethical concerns regarding reproductive technology have been debated in a relatively open manner in comparison with other biomedical issues, according to Shildrick (2004). But despite the technology's potential for unconventional, major disruptions, Shildrick argued that most of the debate has been within conventional ethical frameworks with a focus on individual rights and premised on fixed individual

subjectivity. She considered that the inadequacies of this framework are exposed by the complex reproductive context and she emphasised the need for a post-conventional ethics based on a fluid notion of subjectivity and interrelationships, to better account for collectivist concerns raised by AR. Haraway (2008) insisted on the need for an ethical, realistic approach to encourage accountability for our actions in relation to reproductive technology and Braidotti (2006, pp.9-12) also called for transformative ethics based on a 'non-linear rendering of the subject', and on interconnections and complexities. Braidotti also argued for an ethics of care as being central to social accountability and citizenship in the context of the technologically mediated interconnections of AR. She insisted that care is required in the sense of professional, technical and proficient use of the technology as well as in terms of responsiveness to those being 'cared for' (Braidotti 2006, p.119). So while the following overview of ethical concerns uses a lot of terminology from conventional ethics, this reflects the majority of the debate thus far and should be read in light of Shildrick, Haraway and Braidotti's important criticisms, and on the understanding that these ideas will be discussed in greater detail in the following chapters.

Human rights

The right for all men and women to 'found a family' is enshrined in the United Nations Declaration of Human Rights (UNDHR) 1948. Warnock (1984) considered whether there is a 'right' to have children and she formed the view that there is 'no absolute or even partial right to have children' and that the identity, destiny and happiness of individuals does not depend on parenthood (Frame 2008, p.34). She noted that assisted conception technologies had contributed to a discourse wherein the 'right' to parenthood regardless of the circumstances had come to be perceived as an active right requiring government support to realise this 'right'.

In terms of the rights of children, the special status of children and their need for protection and nurturing is proclaimed in the *United Nations Declaration of the Rights of the Child* (1959, in Frame 2008) with the 'best interests of the child' regarded as paramount. So issues in AR such as the effects on children of conception via anonymous embryo or gamete donation have been debated vigorously and need careful ongoing consideration (e.g. Blyth 2007a) but arguably have been ignored in

terms of regulatory practices (Blyth 2007b). Also issues concerning whether children have a 'right' to both male and female parents and who should therefore be permitted access to AR have been controversial. An example of this is the debate in Victoria in 2008, about broadening eligibility criteria for AR service use to include single people and same-sex couples and whether or not criminal record and other screening/checks should be part of the intake process for AR services. This debate has often been couched in terms of the rights and best interests of children born after AR (see for example, Blackburn-Starza 2008).

In addition to considering human rights issues from an individual rights perspective, Yamin (1997, pp.169 & 177) suggested that an overarching human rights framework is required in women's health. She cautioned that such a framework should not reduce women to 'agglomerations of biological processes or to agents for the production and reproduction of society' rather, that it should take into account the broader social context, including gender relations, socioeconomic issues and equity. She argued that in order for women to be truly self-determining, they need to be 'active participants in the socio-cultural construction of their own reproduction, bodies, sexuality and consciousness' (Yamin 1997, p.177). Importantly she saw that a human rights perspective in health requires health to be recognised as more than biological or technical in its mission; the human rights perspective has the scope to illuminate the power relations and social inequities, particularly women's cumulative disadvantages, as reflected in the realm of health. This argument has clear significance for AR. Blyth and Farrand (2005) also argued for a human rights perspective in the context of assisted conception.

Consequentialism, deontology

The consistent emphasis on outcomes in AR as reflected in data-collection and national reporting formats could be seen as evidence of an underlying consequentialist ethic in service delivery, in that the end result is used to justify the means (Bowles, Collingridge, Curry & Valentine 2006). People who have used reproductive technology to become parents may still be dissatisfied with the quality of service based on their experience of service delivery (Alper, Brinsden, Fischer and Wikland 2002). Because of this, Hamilton (2000) advocated a deontological approach in AR to ensure that the

nature of the process itself is given a high value and so that the acceptability of the technology is based on more than outcome alone (Bowles et al. 2006). This approach is supported by Lambert (2002) and Min et al. (2002, p.5) in their recommendation that outcome measures reflect the live birth rate and should include 'all cycles initiated, regardless of outcome, as the most appropriate because it best represents the burden of treatment endured by a couple'. And while this is now the format for ANZARD reports, other important aspects of AR are still not systematically recorded and the focus is still largely on some outcomes rather than on the process.

For a deontological approach to gain ascendency, experiential information, service-user evaluations and thorough follow-up of all affected by AR are also required to ensure a more comprehensive and inclusive assessment of efficacy and the incorporation of psychosocial aspects of service use. Van Empel, Nelen, Hermens and Kremer (2008, p.1243) extend this by advocating not only for client centredness but also for timeliness in service delivery to be taken into account in considering AR 'success'. They identified six dimensions of quality healthcare, based on deontological principles: safety, effectiveness, client centredness, timeliness, efficiency and equity of access. With the ongoing absence of this range of data in national reporting on AR and while service providers are permitted to report success in such a variety of ways (as previously discussed), the consequentialist approach to service delivery is reinforced and collectivist concerns are not adequately explored.

Non-maleficence, beneficence

Core principles of the medical profession include non-maleficence (avoiding causing harm to others) and beneficence (providing benefit to others) (Banks 2006). In the context of AR, the absence of reliable systematic knowledge about side-effects and long-term effects means that the commitment to non-maleficence and beneficence is at best tentative and hopeful, rather than assured and evidence-based. Lambert (2002, p.3015) discussed the need for AR practitioners to protect their 'human subjects' as a condition of 'medical experimentation on humans'. The duty to thoroughly inform people of the possible health problems of a procedure is regarded as paramount. Lambert discussed these requirements for ethical practice in terms of multiple embryo transfers and argued that gynaecologists treat people 'efficiently but not always safely'

in this context. The discussion presents a major ethical oversight in that it does not account for collective issues due to its individualised approach and it tends to focus on the embryo and fails to adequately consider the health implications, safety and wellbeing of the women.

In pursuit of beneficence and non-maleficence, Olivennes and Frydman (1998) and Pennings and Ombelet (2007) advocated for 'patient friendly IVF'; that assisted conception more closely follows a woman's natural cycles, along with a reduction in pharmaceuticals used to stimulate ovaries and where only one embryo is transferred at a time or GIFT is used in preference to IVF. Van Empel, Nelen, Hermens and Kremer (2008, p.1242) supported this but preferred the term 'quality care' to 'patient friendly' arguing that it more realistically reflected the aim of beneficence in the context of AR procedures arguing that the experience of reproductive technology 'is not pleasant at all' and that to call it 'friendly' would be a misnomer.

The gaps in biomedical knowledge about the technology's outcomes and the narrow epistemological focus of biomedicine also frustrates these ethical ideals of non-maleficence and beneficence. Without ongoing systematic inquiry into the biophysical, psychosocial and other impacts of assisted conception and with continued resistance to including other sources and forms of knowledge into a broader, more stable, inclusive knowledge base, these core principles remain fragile in AR.

Equity, access and justice issues

Policy decisions about eligibility for AR have been debated a great deal over the years, some arguing for unrestricted access, others arguing for a more conservative approach permitting only heterosexual couples access to publicly funded AR. Smith (2006) outlined the 'social' versus 'medical' infertility debate and noted that the construction of infertility itself is a key factor in how government funding and regulation is thereby constructed. It should be noted that arguments for restricting access to 'medical' infertility cases only would have a severe impact on the current client-base of AR clinics. Given that male-factor-only infertility accounts for at least 30% of clients' involuntary childlessness and a proportion of infertility is unexplained, meaning that the female partner is not medically infertile herself and therefore ineligible; her

partnership with an infertile male would, strictly speaking, mean that she is 'socially' infertile. The argument for restricting AR to 'medically' infertile access-only often seems only to thinly veil arguments for greater social control, especially of women and particularly along the lines of hetero-normativity.

Blyth (2007a; 2008b) argued that unrestricted access to reproductive technologies cannot be readily justified on welfare grounds and that serious consideration needed to be given to competing public health and welfare needs. Further, Blyth, Burr and Farrand (2008) suggested that restrictions to AR on the basis of 'child welfare' considerations can sometimes act as a 'smokescreen' for the exclusion of single women, same-sex couples and 'unfit parents' in favour of 'the normative family'. Pennings and Ombelet (2007) also identified cost effectiveness and equity of access as ethical requirements in AR. They argued that the use of community resources must be aimed at maximising wellbeing and that minimal risk and non-maleficence are important aspects of ethical practice in the clinical setting.

Savulescu (1999) outlined some potential benefits of AR, especially for women. He argued that with cryopreservation of ova that 'career women' would be able to achieve equal workforce participation and take their time to find a partner before choosing the most convenient time to reproduce. This argument is based on the assumption that AR is a reliable option when it is not (Molloy, Hall, Ilbery, Irving and Harrison 2009) and also ignores the broader structural inequities in paid employment in society, based on a 'male standard' life experience. So rather than accommodate women's reproductive capacities, this argument aims to 'fit' women into a male pattern of existence and to further fashion AR as to reflect dominant social values and to maintain the *status quo.* He also postulated that maybe only 'the poor' will have sex to reproduce 'in 2099', indicating again that access to AR is stratified and inequitable in terms of socioeconomic status, a point also taken up by Corradi (2008, p.245) as 'white women's privileges and choice'.

Roberts (2004) likewise criticised access to AR as inequitable, especially for non-white people from poorer socioeconomic backgrounds. She also discussed the privatised, marketised nature of assisted conception services and linked this to individualisation,

social control and abrogation of governments' and community responsibility for broader welfare issues.

Conflicts of interest

There is considerable potential for conflicts of interest to occur in the context of AR. The routine ovarian hyperstimulation practiced to ensure larger numbers of ova per stimulated cycle has no therapeutic value for the women involved and has been criticised as a potential conflict of interest, especially since the advent of stem cell research in a marketised environment (Tonti-Filippini, in Skatssoon 2005). Not only does this raise serious questions about the ethics of excess embryo creation and embryo experimentation, the absence of women in most discussions of ethics of embryo and stem cell research is also apparent and disturbing (Sherwin 2007). Skatssoon (2005) also noted that the privatised ownership of many AR services means that there is a profit motive also present; for example, four of the nine licences for human embryo research in Australia in 2005 were owned by one private clinic. George (2008, p.285) argued that egg harvesting and stem cell research cast women at best as 'collateral damage' and that the scientific imperative has been privileged 'seemingly at any cost'. Shildrick (2004) also expressed concerns about the increased emphasis in biomedical discourse on the 'productive power of bodies' in the privatised service delivery context and the possible pressure on people to donate body parts and products (particularly ova) as some sort of moral imperative.

The marketised context of AR also leaves the sector open to questions about conflict of interests in relation to profit motives in service delivery, especially given that most service providers are private companies and that these companies are majority owned by medical practitioners and other clinic staff. In addition, the effectively self-regulated nature of AR in Australia and the lack of demonstrable independence of review committees (e.g. ARTRC) and accreditation boards (FSA, RTAC) does little to minimise potential conflicts of interest in relation to regulatory standards and requirements, lobbying and consultation about the level of public funding and reporting requirements.

For example, despite the terms of reference for the Independent Review of Assisted Reproductive Technologies (ARTRC 2006) including clinical as well as policy, societal and 'other relevant matters', the review committee did not include any representation from service users and only limited representation outside the biomedical sphere; of the six committee members, four were men and five were biomedical scientists or medical practitioners working in reproductive health. The committee reported that due to time constraints public submissions could not be sought and instead they held consultations with key stakeholders. Representatives from ACCESS Australia (a consumer advocacy and support group largely funded by biotechnology companies and AR clinics) were included amongst the key stakeholders along with representatives from the FSA and the IVF Directors' group. With a committee of this composition and with such limited consultation, the independence of this review is difficult to defend and the argument that the gatekeepers of infertility advice are the reproductive industry themselves seems to have credence (Abboud 2005).

Religious and spiritual objections

A detailed exploration of the range of religious opinions on AR is not possible within the limits of this study so an overview of the major themes is provided here. Many of the major religions share similar views on the ethics of assisted reproduction in terms of the belief that sexual intercourse between married heterosexual couples is the only permissible way to conceive a child. Many also assert the sanctity of embryonic human life and believe that life begins at conception. Catholicism permits no intervention in conception at all outside of sexual intercourse (Ford 2008) and Greek Orthodoxy is very similar in this regard. The Greek Orthodox religion considers AR to be dehumanising and argues that assisted conception desecrates human conception (Nikolaos 2008).

The Islamic position is somewhat different in that AR is permissible for married heterosexual couples based on the Islamic value of encouraging family formation. Also in Islam, unlike Greek Orthodoxy and Catholicism, embryo experimentation is permissible up until fourteen days after conception – the time at which a conceptus is regarded as an individual (Serour 2008). Some ethicists regard religious explanations and ethical frameworks as inadequate bases for considering the complexities of the

modern range of reproductive possibilities arguing that they are at best obsolete and at worst 'dangerous' (e.g. Mori 2008).

Gametes, embryos, surrogacy

Other ethical issues surrounding gamete and embryo production, surrogacy and possible 'trade' have also been identified. Over 100,000 embryos are in storage in Australia (Christopher 2006) and while most of these embryos will be used by their parents, some will remain in storage and decisions will eventually need to be made as to their fate. Embryos can remain in storage for up to ten years in Australia, depending on jurisdiction. RTAC guidelines recommend the ten-year storage maximum with the possibility of extending storage two years at a time if indicated. The options open to most service users include continued attempts to achieve pregnancy via frozen embryo transfers, donating the embryo(s) for research purposes or to other service users or to let the embryos thaw and perish. Open trade and commercialisation of embryos and ova is not permitted in Australia, nor is commercial surrogacy, although altruistic surrogacy is permitted in most jurisdictions. Internationally however, there is concern about the trafficking of human gametes and embryos in particular with developing countries being used as a source for these commoditised human 'products' (Roberts 2004).

In several Australian and international studies, decision-making patterns and preferences in relation to the storage and destination of embryos are fairly consistent; most service users agree that the decision is very difficult in the first place and most also found that donating to other people for embryo transfer and possible pregnancy is the least preferred option (Burton & Sanders 2004; de Lacey 2006; McMahon, Gibson, Leslie, Saunders, Porter & Tennant 2003; McMahon & Saunders 2007). These studies also consistently reported that service users often regard embryos as their children, especially if they have had children previously as the result of AR. This attachment to embryos as children or potential children means that considerations about donation to other couples include issues similar to conventional adoption. People are concerned for the wellbeing and life chances of the embryos and many feel that relinquishing them will be an ongoing grief and too great a loss to bear.

Other controversies relating to gamete donation include donor anonymity, secrecy (especially surrounding male infertility), donor-children's access to identifying information about their genetic origins and open-kinship and parenting arrangements after assisted conception (Blyth 1999b). Thus the issue of genuine consent in relation to gamete donation remains controversial and 'informed judgement on empirical grounds cannot yet be made' (Blyth and Golding 2008, p.465).

While donation to research and discarding embryos is regarded as a significant loss, most of the literature consistently points to these options as being preferred over donation to other couples for procreation, largely because there is at least a definitive end-point with these options, unlike donation for procreative purposes (de Lacey 2007). Due to the gravity of decision-making in this context, Burton and Sanders' (2004) research indicated that most couples would prefer to have access to professional psychosocial support in this decision-making, with only 10% of people indicating that they felt they could make the decision without such input. Fuscaldo, Russell and Gillam (2007) likewise recommended professional counselling support and more information about embryo destination options be provided to service users to assist in the decision-making process. Newton, Fisher, Feyles, Tekpetey, Hughes and Isaacsson (2007) found in their study of Canadian service users, that people also change their preferences about surplus embryo destination during their period of service use and once AR use is discontinued. In recognition of this, they recommended a two-stage decision-making consent process.

Genetic testing and embryo screening and selection practices in AR also raise ethical issues in relation to what is considered a 'good' or 'healthy' or 'desirable' about embryos, and what is not. Osburn (2007, p.86) discussed the ethics of pre-implantation genetic testing and warns against the broader societal impacts of this increasing practice – 'eugenics by stealth'. Shildrick (2004) and Dominelli (2002) highlighted the 'disablist' approach to reproduction that occurs when only 'perfect' embryos are selected, reinforcing disability as an undesirable medical condition, rather than as a social construction. Shildrick (2004) argued that genetic technologies have major implications for the human species, not only individuals and that genetic testing does

not offer correction or cure but only elimination of genetic 'anomalies'. Significantly, Shildrick also questioned the basis upon which decisions are made about the 'right' phenotype(s) to preserve.

Mytituik & Nisker (2007) also placed embryos in a broader context arguing that embryo health is a multidimensional process and that social determinants of health as well as access and equity issues in society affect notions of embryo health and as such decisions about embryo 'quality' have a broader social impact, especially given that access to AR is still stratified and that it is largely a middle-class service-user phenomenon. They also noted the need to assess health priorities so that ethical, legal and social issues are taken into account in addition to biomedical considerations. The research interests, financial interests and possible conflicts of interest in AR clinics also need to be considered as another layer of complexity and source of potential ethical issues.

Informed consent and self-determination

Because AR is often represented as 'an established science' and as 'routine' this tends to downplay any associated risks as well as the high rates of technological failure (Sharp 2000). Whether women are adequately informed of the risks is highly debatable and this represents a significant ethical issue in terms of client decision-making and informed consent. This coupled with often unrealistic representations and expectations of success, this produces an ethically risky situation (Ewing 1992; Hellwege 1999; Hoffman-Baruch, D'Adamo & Seager 1988; Klein 1989a & 1989b; Murdoch 1985; NHMRC 1998; Peddie et al. 2005; Reed 2001).

Klein (1989b), Ewing (1992) and NHMRC (1998) reported on the lack of accurate information on risks and outcomes for AR clients. In an NHMRC (1998, pp.39-41) survey of AR clinic information brochures, it was noted that not all mentioned the main adverse outcomes of procedures. It was also noted that the information was often conveyed in an overly positive, reassuring tone which tended to downplay risks. Given that many service users are seeking assistance with reproduction usually in the midst of a great deal of stress and concern about involuntary childlessness, the need for clear, accurate and full information is vital.

Barnby (1995, p.2) described her state of mind as 'desperate' when she was seeking help in becoming pregnant, she says that she felt 'consumed' and that 'I don't think I'd cared what I did to achieve a pregnancy'. Further she said that 'desperation leads people to be more trusting and to ask fewer questions and take greater risks than they might ordinarily do'. Leiblum, Aviv & Harmer (1998, p. 3574) also sounded a note of caution about the susceptibility of AR clients to 'unscrupulous and overly optimistic practitioners' and urge fertility specialists to 'be responsible in what they promise'. Porter and Bhattacharya (2008) in their research on service users' satisfaction with the quality of information provided by clinics in Scotland and service users' satisfaction, found that most couples were dissatisfied with the written and verbal information provided to them and that they had supplemented this by using the internet, books and magazines. The combination of highly motivated clients and incomplete or otherwise unsatisfactory provision of information ensures that informed consent is difficult to enact and thereby self-determination is compromised.

Gupta and Richters (2008) explored whether it is possible for women to enact self-determination at all if their personhood and bodily integrity is lost in the process of AR. They also questioned whether women (and men) have proprietary rights over their body parts in a neoliberal, globalised trade environment. Gupta and Richters (2008, p.247) concluded that despite objectification, women are exercising self-determination when they use reproductive technologies in that they are not simply acquiescing, but responding 'actively and strategically to achieve desired outcomes'. And while this argument has some appeal and while they acknowledge that AR procedures are difficult, they do not adequately address the lack of reliability of the technology in achieving its outcomes and consumer awareness of this. Without addressing this significant issue, the prospect of self-determination in AR remains compromised.

Presumably most women and their partners use AR to try to achieve pregnancy and live birth. If this is the case, then AR is only a possible solution. For self-determination to have been truly enacted all parties concerned must be cognisant of that fact, otherwise the decision to pursue AR is based on misinformation. If however people approach AR use as a way to cope with involuntary childlessness and fully understand

that there is only a chance and not a surety of achieving a live birth and if all salient known and unknown factors (like risk of harm for example) are discussed, then there is a firmer basis for arguing that service users are self determining.

Also in relation to self-determination, Klein (1989a, pp.6-7) argued that the pro-natalist nature of our society does not allow a full range of options to be available to women. She argued that only when childlessness is not seen as 'second best' and as having to be 'overcome by having one's own biological child' will there be real choice to 'say no to IVF'. So for her, the absence of a range of validated social roles for women in society equates with an absence of real choice and therefore real self-determination in relation to reproductive choice and technology.

 In addition to these ethical questions, there are considerable emotional, physical, spiritual and opportunity costs of undergoing AR procedures plus substantial financial costs to the State and the individual. These are now explored.

Social research and critique of assisted reproduction

Encouragingly, Inhorn and Van Balen (2002) asserted that the discourse of reproductive technologies increasingly includes the perceived social and economic consequences of infertility as well as biomedical considerations. Even if the broader impacts of the technology are increasingly being validated, it could still be argued that the dominant discourse continues to privilege biomedical research and any social research it validates tends to emanate from the positivist mode of inquiry.

The impacts of reproductive technologies have been the focus of a great deal of research since at least the late 1970s, with a large proportion of that research coming from the positivist mode, reinforcing dualist and universalist themes in the dominant biomedical discourse. Specifically, psychometric and other research following traditional experimental design, using standardised instruments and methodology fits well with the biomedical approach and often obfuscates the broader, more complex nature of AR and treats service users as objects of study rather than as self-determining subjects.

For example, Chen, Chang, Tsai and Juang (2004, p.2313) used a 'diagnostic' interview schedule to assess clients' 'depression and anxiety disorders' and conclude that there is 'an extraordinarily high prevalence of generalised anxiety disorder' amongst women clients of an AR clinic in Taipei, Taiwan. Their research approaches women as 'patients' and medicalises infertility. They did however acknowledge the cultural context of their research and how Taiwanese social values may also impact on women's distress about childlessness but the overall tone of the research is positivist and modernist and aimed toward a universalist position about the effects of individuals' anxiety on the success rate of AR. People were placed in the category of 'patient' and feelings of anxiety and depression were seen as symptoms to be treated.

Similarly, Eugster and Vingerhoets (1999) administered psychometric tests to a group of AR clients pre-service and post-service use to measure psychological adjustment and Smeenk, Verhak, Eugster, Van Minnen, Zielhuis and Braat (2001) tried to measure pre-existing psychological factors. Both studies found that individual pathologies impacted on AR outcomes and that treating and decreasing stress would mean increased AR success. There was less emphasis on questioning the need for improved clinical effectiveness in reproductive technology itself and this approach serves to isolate, pathologise and individualise service users.

This type of approach to service users' experiences is typical of articles appearing in mainstream AR journals and conference programs and is based on an epistemological position that privileges the researcher and the instruments used in measurement, rather than the clients' range of experiences and characteristics. People's distress is couched in terms of 'negative emotional symptoms in infertile persons', 'symptoms that need to be "treated" usually via individual therapy' (De Liz and Strauss 2005, p.1324). Much of this research advocates stress reduction 'treatments', cognitive behaviour therapy, etcetera, to remediate these issues. And while it is acknowledged that the intent may be good – to make the experience less stressful for service users – the effect, whether intended or not, shifts the focus from the technology itself and often posits responsibility for failure onto individuals, mostly women, rather than on a

lack of clinical effectiveness in AR technology or on the lack of clinical expertise in administering the technology, thereby helping to maintain the dominant discourse.

While this type of research has value in shedding some light on various psychosocial concerns, it also often has the limitation of being narrowly focused and deductive and because of its dominance and privileged place within the superstructure of the biomedical discourse, it could be charged with perpetuating the disempowerment of service users and of relegating women in particular to object rather than subject status. For a firmer epistemological base, qualitative research also needs to be pursued on an ongoing basis and this research needs to be validated within a more appropriate, less restrictive knowledge base to facilitate a broader, bio-psycho-social approach and a more solid foundation of knowledge in AR (Kainz 2001).

An overview of feminist critique is provided in the next chapter, drawing on work that has an explicit feminist frame of reference and a focus on gender relations in assisted reproduction. But before focusing on feminist work some further social research on lived experiences of AR will be explored.

Other social research and commentary

Other qualitative, phenomenological research and personal accounts of women's experiences of AR indicate a range of feelings about AR. Many women feel physically, emotionally and financially drained by involvement in AR and many also express positive feelings about reproductive technology as an option to possibly redress involuntary childlessness. Some describe feeling empowered by having this option when they perceive that there are no other viable options to achieve what they desire. Many women have also reported feelings of objectification, commoditisation and alienation – of feeling 'pried apart' (McKean 2002 in MIVF 2004, p.1). Anxiety, depression, conflict in relationships, disruptions to other life commitments, anger and powerlessness are often also part of women's reported experiences.

Sinclair (2003, p.4) described her experience of IVF as 'drawn out, invasive and uncomfortable … heartbreaking but almost impossible to abandon'. She also described how 'uncertainty seeps into every aspect of life' and that planning for many aspects of life often hinged on the timing of IVF procedures – 'as long as you're in the program,

your life is in limbo' (Sinclair 2003, p.4). Other personal accounts of AR (see for example Berman 2006; Miller 2007; MIVF 2004) describe how it can be experienced as a proactive step to redress involuntary childlessness but also how it can dominate people's lives and often impacts on women's ability to meet work, family and other commitments.

Some women report frustration and dissatisfaction that they had been given hope but insufficient information (MIVF 2004; Murdoch 1985; Peddie et al. 2005; Porter & Bhattacharya 2008). Others have also noted that service use is often long, stressful, disheartening and invasive and that it involves many painful procedures (Daniluk 2001; MIVF 2004; Selis 1999). Much has been written about the physical and emotional pain of AR procedures, including mood swings, pain from injections, nausea, depression, reactions to pharmaceuticals, bruising, swelling, abdominal pain, ovarian swelling and pain, headaches, etc. (Baker 2003). Selis (1999, p.32) described his partner's experience as 'reproduction robbed of meaning, denuded of pleasure, and stripped of joy' and many have described feeling 'almost constant loss and grief' (Dudzik 2002 in MIVF 2004, p.1).

In a qualitative study of women's experiences of AR in the United Kingdom, Redshaw, Hockley and Davidson (2007) found that women consistently identified that being treated with respect and dignity and being given sufficient information and support was vital to a satisfactory experience of reproductive services. This study is significant in that it focused on women who achieved successful pregnancy and live birth outcomes from AR where many other studies have either focussed on those for whom AR was unsuccessful or a mixed sample.

For women living outside of metropolitan areas in the regional, rural and remote areas of Australia, these impacts are amplified by intersectional disadvantages they face such as reduced access to a range of health and allied health professionals, distance, and broader rural socioeconomic disadvantage (Alston, Allan, Deitsch, Shankar, Osburn, Bell, Meunstermann, Giorgas, Moore, Jennett, Ritter, Gibson, Wallace, Harris, & Grantley 2006; ARTRC 2006). Masters' (2000) account of her experiences of IVF detailed the added opportunity costs for rural women and their partners as well as the

particular work and lifestyle difficulties faced by farmers, such as having to organise caretakers for livestock and crops during absences from the farm. Masters also discussed the difficulties of maintaining privacy in many smaller rural communities and the intrusiveness of community members' enquiries about procreation. She identified the 'unwritten rule, very quickly transmitted, against talking to any of the other patients in the IVF clinic waiting room' (Masters 2000, p.22). Masters also described her use of selective disclosure to reduce the need for repetitive explanations, especially about repeated AR cycle failures.

Despite these significant impacts, many service users have indicated how difficult it is to cease AR and to accept that there is 'not always a baby at the end of the line' (Coffey 2004 in MIVF 2004, p. 2). Peddie et al. (2005) in their qualitative research of women's decision-making to end AR, identified a range of reasons for cessation of service use, including: stress associated with AR cycles and ongoing childlessness, unmet expectations of success and ongoing failure, insufficient personalised information, social and professional opportunity costs, physical and emotional stress on relationship with partner, and a lack of psychosocial support from the service provider. Peddie et al. also reported on the factors influencing continuation of AR use, and these included: the inability to accept childlessness and using service-use as a way to delay accepting infertility, ongoing hope of success, media coverage of 'breakthroughs' and implied pressure to 'keep trying' by altering aspects of the AR regime. In Arndt's (2005, p.176) survey of eight hundred and eighty Australian women, the cost of AR was identified as a major reason for discontinuing use, followed by emotional stress, with 91% of respondents indicating that they would try AR again if a new procedure became available.

For some clients, the most positive aspect of the experience will obviously be the birth of a healthy baby. For others, the most positive aspect has been the opportunity to do something active and constructive about involuntary childlessness, providing a sense of control and empowerment over the 'hopelessness' and 'heartache of infertility' (Solomon 2004 in MIVF 2004, p. 2; Porter & Bhattacharya 2008). It can be argued that the medicalisation of infertility has also had the effect of legitimising the impacts of

infertility and that AR thus empowers people to take action to alleviate involuntary childlessness (Roach Anleu 1999). AR can be said to offer at the very least, the prospect of hope where before there may have been none.

Longer term impacts of service use have also been explored by some researchers although after cessation of AR, many clients 'are generally lost to follow-up' (Leiblum et al. 1998, p. 3569). Leiblum et al. (1998) compared longer term outcomes for women who had successfully borne a child through AR, women who had not had success with AR but had adopted a child and women who had no success and who remained childless. They found that the childless women described the most serious negative impacts on relationships and life satisfaction overall, but that still some positives were described. For example, some described AR as having brought closeness to the marital relationship and that the sharing of the AR experience had been positive overall, despite a lack of success.

In Australia, Hammarberg, Astbury and Baker (2001) conducted a follow-up survey of women two to three years post-AR. They found that a successful outcome was linked to a more positive recall of the AR experience, but that in general, the experience was considered emotionally, physically and financially costly. Some of the key findings include that the median number of years spent trying to conceive a baby via AR was three and a half years (with a range of 1-10 years), that most were satisfied with the procedural information their clinic provided, but less satisfied with information about the psychosocial impacts of service use. They also found, as other studies have, that most people over-estimated the likelihood of success and that 25% grossly overestimated their chances of having a baby via IVF. The longer term effects of AR on parenting was explored by Golombok, Breways, Giavazzi, Guerra, Mac Callum and Rust (2002) and they found some evidence of parental 'over-involvement' in AR children's lives but no evidence of marital problems in the long term. Their research is limited however to couples who achieved success through AR, so their findings in relation to marital disharmony are limited in that respect.

Based on the volume of previous social and other research into reproductive technologies and based on the complexity and multidimensional nature of AR, the

level of interest in reproductive technologies appears likely to be sustained into the foreseeable future. For example, Blyth's (2008a) international project exploring people's experiences of reproductive health care using an online survey to gather their stories. And according to Inhorn and Bierenbaum-Carmeli (2008, p.177) more than fifty anthropologists worldwide were known to be studying AR in 2008. They also reasoned that the destabilising and generative impacts of AR and its 'interface between science and society' make it a field of ongoing interest to theorists from a range of academic disciplines.

Many would argue that while ever the biomedical discourse remains so resolutely impermeable to other discussions, the work of feminist, other social researchers and commentators, to create a broader, more fluid discourse and knowledge base is unfinished. However that is not to say there is a static, universal endpoint in this task. Rather the field is likely to remain contested and dynamic.

Psychosocial support

Worldwide, social workers, psychologists and other human service professionals play a role in counselling in the context of reproductive health (Osburn 2007) and there is general support in the literature for service providers to address psychosocial issues related to involuntary childlessness and AR service use. Given the nature of AR and the emotional, financial, spiritual and physical investments made in it, it is reasonable to suggest that clients have needs for support, both formal support from service providers and informal support from family and friends. Franklin (1997) found that women appreciated the support of their partners as a crucial element in coping with AR. Some argue however that while an understanding of support needs is important, that more energy has been devoted to the social and psychological hazards of AR on women than to the health risks (Kirejczyk 2008). Previous research indicates that service users are often disappointed by the lack of communication skills and psychosocial support demonstrated by medical practitioners. Some participants in Peddie et al.'s (2005) research felt that their doctor was unprofessional, lacked compassion and often appeared detached and unfamiliar with their circumstances.

51

Women have identified a need for support at the time infertility is confirmed, at the commencement of service use, during service use and afterwards (Ewing 1992; Murdoch 1985; NHMRC 1998). In the *Review of the Human Tissue Act 1983*, *Discussion paper on assisted reproductive technologies* (1997) the FSA (s.3.6) recommended counselling as an integral part of AR programs (FSA 2002; NSW Department of Health 1997). Counselling is mandatory in some Australian states and is accessible to varying degrees often dependent on location. Counsellors working in Australian AR clinics must be a member of the Australia and New Zealand Infertility Counsellors' Association (ANZICA), an organisation affiliated with the FSA and RTAC. ANZICA was established in 1989 and requires full members to be qualified social workers or psychologists with associate membership for nurse-qualified and other counsellors (ANZICA 2008). Clients in metropolitan areas and some larger regional centres generally have better access to a range of professional support; clients in more isolated areas often have very limited access to such support.

Internationally, Emery, Beran, Darwiche, Oppizzi, Joris, Capel, Guex and Germond (2003) noted that many jurisdictions have made counselling mandatory and that ideally mandatory counselling should not be regarded as a one-off occurrence. They advocate for a preventative model based on an initial narrative-based interview with appropriate follow-up counselling, rather than a crisis driven model. Hammarberg et al. (2001) found that when counselling is mandatory (as it is in the state of Victoria where they did their research) that only 15% of service users had more than the one mandatory session with a counsellor. The majority of participants in that research however also said that ongoing counselling should be part of AR especially in relation to the decision to end service use. Peddie et al. (2005) recommended improvements in counselling services to better prepare clients for the social and emotional impacts of AR, to improve the quality of communication between clients and clinic staff and to provide adequate follow-up support for clients.

Klein (1989b) found that many women felt that the counselling available to them upon entering AR clinics did not adequately prepare them for the range of physical, emotional and spiritual effects of the treatment. Her research also identified that

many women find it difficult to develop enough trust for a meaningful relationship with their counsellor, due to the counsellor's direct link to a clinic and the *perception* that all had better 'be well' or their place in the program could be jeopardised (Klein 1989b, p.23). The need for independent counselling was also highlighted by Ewing (1992). Further, the lack of adequate follow-up counselling was identified as an issue in Klein's research, as it was in Peddie et al. (2005). In the absence of access to independent counselling as part of AR programs, there is a risk of 'in-house' counselling being perceived as tokenistic. However, the additional costs of accessing independent counselling may be prohibitive, especially given the high costs already borne by clients.

Some clients have described counselling in very positive terms and many note the importance of having a range of support mechanisms in place, including support groups, newsletters and online groups (MIVF 2004). Counselling was also identified as helpful for clients in accepting infertility and in 'moving on', for grief and loss, pregnancy loss, donor issues, frozen embryo issues and general emotional support (MIVF 2004). The need for a range of ongoing support options such professional, individual counselling, professionally facilitated information and/or support groups as well as access to video resources, written material, telephone counselling and client-initiated self-help groups is also advocated by Emery et al. (2003). To this list Lemmens, Vervacke, Enzlin, Bajelants, Vanderschoren, Hooge and Demyttenare (2004, p.1918) add couple counselling, art therapy and 'mind-body therapy' to 'reinforce the oneness' of body and mind. Hammer-Burns (1999) also discussed the need for service providers to approach the care of service users in a holistic, unified manner – 'unity between the medical and psychosocial team' (Emery et al. 2003, p.2652) an aim also supported by Haase (2007, p.1) who insisted that 'the medical domain alone cannot sufficiently address all the ethical and psychosocial ramifications' of AR.

Hammer-Burns (1999) advocated for a multidisciplinary team approach to AR, a move away from a purely biomedical approach to mutual participation and to narrative models of practice. Systemic approaches to AR would facilitate a redressing of the mind-body split and create a more humane, holistic environment for women and their

partners. The predominance of biomedical approaches and life crisis models in AR clinics reinforces the individualisation and alienation of women and their partners. By neglecting the broader context of AR, the various serious risks, costs, improvements and implications of the technology continue to be obscured.

Previous research into clients' experiences of AR has generally stopped short of specifically exploring women's support needs and has not adequately considered the effectiveness of the counselling and other support services that some women receive at AR clinics. Dominelli (2002, p.72) urged social workers to take a more active role in 'rethinking the implications of ...reproductive technologies' and in refocusing AR on women's rights, active participation, wellbeing and social justice. Research focussing on the contemporary Australian context of support service provision is needed, particularly for regional and satellite clinics given the significant access issues faced by this group.

This chapter has presented some of the major ethical, social and religious debates in relation to human reproductive technology. The power of reproductive technology to disrupt a wide-range of psychosocial, ethical, legal and spiritual dimensions has been explored in general but perhaps the most potent disruptions relate to gender. Thus, the next chapter focuses specifically on feminist critique of AR and provides a summary of the overall review of literature, linking it to the theoretical framework for this research and the methodology.

Chapter 4 - Feminist critique

Feminist critique of reproductive technologies has been described as coming in waves: the first wave as essentially radical feminist, the second as incorporating more liberal feminist concerns and increased critique of the impacts of technology and the medicalisation of reproduction, and the third wave more characterised by post modernism and a burgeoning post-structural orientation (Frame 2008; Thompson 2005). These waves are not necessarily neatly delineated and many theorists' work spans two and sometimes all three phases of critique.

First wave feminist critique

The first wave of feminist critique centred on the masculinist medicalisation of reproductive issues such as new reproductive technologies, pregnancy and childbirth. The critical voices were not uniform and some feminists, such as Shulamith Firestone (1970), saw the potential of reproductive technology to release women from the burden of pregnancy and childbirth. The predominant view was however that AR increased, not decreased, 'subservience to biological destiny' (Thompson 2005, p.57). Other sources of resistance to new reproductive technologies came from conservative and religious groups, which at times lead to uneasy alliances in the critique of the social, ethical and legal implications of the technology. Arditti, Duelli-Klein and Minden (1984), Corea (1988), Crowe (1985), and Klein (1989 a & b) are exemplars of the first wave of feminist critique. In 1985, the Feminist International Network of Resistance to Reproductive and Genetic Engineering (FINRRAGE) was established and called for 'a different kind of science and technology that respects the dignity of womankind and all life on earth' (Thompson 2005, p.59). Even at this early stage, feminist critique was multidimensional and not exclusively or narrowly focussed at the individual level or the societal level. There was an emphasis on epistemological and philosophical concerns as well as on the impacts of AR on individuals and society.

To gauge the nature of impacts on individuals' engagement with women who had direct experiential knowledge of the technology was integrated into this critique. Crowe (1985, p.547) surveyed women in Sydney, Australia, about what motivated them to use reproductive technology and even at this relatively early phase of service

provision, she found that the sector mirrored 'power relations between males and females' and that the most likely women to be motivated to use AR are those who adhere to the dominant ideology about motherhood and the discourse of infertility and who could accept the dynamics of male dominated medical science. This, according to Corea (1988, p.89), meant that reproductive technologies threaten to 'remove the last woman-centred process from us' and reinforced the message that technology is best – 'better than women'. Unlike Firestone's utopian vision of liberation via freedom from reproduction, Corea argued that women in fact needed to control their reproductive capacity and that social change is required to validate this capacity. In later second wave critique, Greer (1999, p.84) also rejected Firestone's vision saying that to lose the reproductive role would be 'the end of women altogether'.

In Klein's (1989b) study of women who had used AR most respondents identified feeling de-personalised during their involvement, that their emotional needs had not been recognised and that the most positive aspect of their experience was the support from other women attending the clinic (Klein 1989b, p.27). Klein saw AR as being 'a new form of violence against women' (Klein 1989b, p.8) and as reinforcing gender inequalities by focussing on and reinforcing the gender politics of women's biological role in reproduction. Likewise Hoffman Baruch et al. (1988, p.136) described reproductive technology as 'the new misogyny' and as the 'plundering of private space' which serves to exacerbate the effects of the deprivation of public space on women.

In the late 1980s, Klein sounded caution about the relatively rapid expansion of AR services in Australia and the marketing practices of these services. She said that this expansion and promotion of AR was resulting in the 'infertility market' becoming a 'booming business not to be underestimated' (Klein 1989a, p.248). Klein has sustained her activism and critique of reproductive technologies into the current 'wave' of critique and many of her earlier concerns have been borne out, particularly in relation to the commoditisation of women and body parts and global trade in reproductive material (Klein 2008). Klein remains a critic of the notion that AR provides women with

real reproductive choice, arguing that this 'choice' is a liberal feminist notion and that in reality it is still nothing more than another form of social control of women.

Another attempt to claim space for women in these relatively early days of assisted reproduction was made by Rowland (1988). She identified the need for women-centred laws and regulation of new reproductive technologies. She also detailed her concerns about experimentation, welfare, eugenics, masculinist science and ethics in AR. Many of these concerns are documented by Rutnam (1991) who identified the initial reluctance of Australian governments in the mid 1980s to fund AR because of its experimental stage of development. She also detailed safety concerns of key feminist critics like Klein and Rowland in addition to concerns published by the NPSU in 1987 as well as other research substantially challenging the clinical and cost effectiveness of the procedures (e.g. Bartels 1987, in Rutnam 1991). One of the technology's main proponents even described IVF as having 'relatively low success' and as being suitable 'only for the most determined couples' (Trounson 1989, in Rutnam 1991, p.96). Despite these misgivings, Medicare funding for AR commenced in the 1990 Federal Budget with the government's somewhat circular position at the time being that AR was no longer experimental by virtue of the number of babies already born after AR (Rutnam 1991, p.95).

The combination of an active, powerful pro-IVF lobby and the relatively generous public funding of AR at this time led to a shift in feminist critique. A position of absolute resistance was proving difficult in the face of this level of acceptance internationally and in Australia.

Second wave feminist critique

As reproductive technologies normalised their place in the biomedical and social landscapes, as regulatory frameworks and government funding regimes were developed and as service user advocacy groups like ACCESS were established, the 'just say no' form of resistance of the early first wave phase gave way to the second wave feminist critique in the early 1990s. Thompson (2005, p.61) argued that much of the impetus of the first wave critique was undermined in the mid-1980s by pharmaceutical companies and service providers filling an information gap for consumers by publishing

a range of material about AR for service users. Thompson noted that much of this material remains a standard feature in many AR clinics today and she argued that this 'mainstreaming of criticism' served to undermine the force of the radical critique by building up the patient friendliness of AR. Along with the mainstreaming of criticism, the dismissal of criticism is also apparent in some of the musings of AR service providers of the time. For example, Jansen (1999, p.666) stated that IVF 'confers certainty' in overcoming 'many types of infertility' and that 'objections to IVF on moral grounds have long since been in the minority in Australia', although the evidence for this claim is not made clear.

Some second wave critique emphasised the need to engage with AR and on how best to manage the technology. Although this type of liberal critique was more visible during this time and until the turn of the century (Frame 2008) critique during this period was not exclusively 'ameliorating', accommodating and liberal. Many first wave critics continued their work into this time and a range of important researchers and theorists emerged to add their voices to the knowledge base of AR. Arguments about comparative health funding and the ethics of public funding to highly technical and unreliable forms of medicine at the expense of spending on preventative and basic health services gathered momentum in this phase (Thompson 2005).

Klein (1990) continued to urge resistance to AR saying its primary purpose was to create embryos and not to work towards women's needs. She surveyed women for whom the technology had been unsuccessful and her findings echo earlier research findings that these women felt objectified during their experience – 'like a cow' – and that women and not the technology were often blamed for the lack of successful outcome. Many of these women had also experienced that medical practitioners lacked empathy and communication skills and were not interested in them as people.

Koch (1990) did not advocate outright resistance to AR but argued that there was a need to keep questioning the allocation of resources to such a clinically ineffective technology. Koch was critical of the influence of practitioners and biomedical researchers on policy decisions and argued for clinics to provide better psychosocial support. Koch also provided a framework to establish the rationality of women's

decisions to use AR. She called the choice to use AR a 'strategy of action' because AR is an established option and that the aim in using it could be seen as an active response to childlessness in an attempt to resolve the reproductive future. This more nuanced approach to rationality in the context of assisted conception means that the decision is rational if it is made on the basis of clear information that a live baby at the end is not an assured outcome. Koch's ideas are echoed by Gupta and Richters (2008), as discussed earlier. Again however, for this position to be maintained there must be good quality, accessible, reliable information about clinical effectiveness provided to clients; an important and often still not realised feature of AR service delivery.

Rowland (1992) and Hepburn (1992) continued the critique of gender power relations initiated in the first wave of feminist critique and highlighted the powerful potential of commerce and biomedicine in the control of procreation. Raymond (1994, p.ix) also perpetuated first wave concerns about AR as 'publically sanctioned violence' and the continued separation of private and public spheres as a way to maintain the *status quo*. She resisted the second wave liberal feminist accommodation of AR as a woman's private reproductive choice, arguing that this notion of 'choice' only serves to obscure the damage done to women and to society by reproductive technology. Just as many first wave critics before her had argued, she maintained that abolition, not regulation was the best option.

Ginsburg and Rapp (1995) reiterated first wave feminist concerns about the highly stratified nature of access to the technology - Greer (1984) as one example. They also outlined the discursive shifts occurring in AR whereby natural conception was increasingly conflated with assisted conception and at times, natural conception was cast as 'faulty' and needing technology to improve it. Examples of this conflation of natural and assisted conception and of the medicalisation and fragmentation of reproduction are found in Jansen (1999). Jansen stated that IVF makes impregnation 'a non-essential side-effect of sex', and that whether fertilisation 'is internal or in-vitro', that 'conception need not be internal for a woman to reproduce'. These types of comments by service providers helped to focus second wave critique on the huge potential for AR to disrupt kinship patterns and for it to raise considerable new ethical

dilemmas, regulatory issues and to remind feminists that the development of the technology was proceeding at times with very little regard for what women might actually want.

Shildrick (1997, pp.181-189) elaborated on the relative absence in medical literature of women as active subjects in their own right. She used AR as an effective way to critique the ontological and epistemological bases of modernist knowledge. Shildrick used a feminist post-structuralist approach to argue for a fluid notion of subjectivity as opposed to a fixed, impermeably bounded subject saying that AR itself presented 'dilemmas irresolvable within conventional paradigms' and that some procedures represent a threat to 'the very centre of phallocentric order'. This important work drew on Luce Irigaray's ideas about dual subjectivity as well as Foucauldian notions about power and knowledge. Because of the centrality of Shildrick's work to the re-envisioning of AR, it will be discussed in greater detail in the next chapter.

Franklin and Ragone (1998) explored AR as a cultural practice and also considered its kinship, power and technological implications. Importantly, this work also critiqued the knowledge base of AR and its dependence on disembodiment and fragmentation and highlighted the epistemic crisis of a technology the success and reliability of which cannot be established. This epistemological crisis is as yet unresolved and the paradox of AR maintaining its dependence on a linear cause/effect, treatment/cure biomedical model despite its own evidence to the contrary remains a feature of the AR to this day.

In this phase of the feminist critique a more nuanced theorising of infertility and reproductive technology began to take shape in the context of the validation of women's maternal roles and desires being defined as authentic and not simply as a patriarchal mandate to reproduce (Sandelowski 1990). The desire of many women to be mothers and the centrality of the virtues of motherhood as a basis for real social change gained power via post-structuralism and developments in feminist theory (Thompson 2005). Greer (1999, pp.76 & 205) asserted that AR split motherhood into three categories: gestational motherhood, genetic motherhood and parental motherhood. She confirmed the need for feminism to prioritise the conceptualisation

of 'dignified motherhood' and to resist the notion of 'man-made motherhood' in which women's fertility becomes a medical problem.

Theorists such as Rapp (1988 & 1999), Franklin (1997) and Raymond (1993) also explored the complex range of possibilities for women, kinship and AR and recognised the importance of experiential knowledge and variations. Franklin's phenomenological research emphasised the potential for AR to challenge cultural assumptions about procreation and she continued to document how AR conflates nature and culture in the dominant discourse. Her work revealed how many regard having children as a way to fulfil and 'complete' the marital relationship. Franklin, and others, have been criticised for their heterosexist bias and for a failure to problematise and theorise heterosexuality as a basis for the reproductive imaginary (Nordqvist 2008, p.288). Haraway (1997) continued to question the stratification of reproduction and which social groups have access to AR. Importantly she also questioned the nature of scientific knowledge and discourse, arguing that the dualist nature/culture split was a myth and that we are all composed of natural, social, cultural and technological aspects – her cyborg manifesto. Haraway's work will be discussed in the following chapter.

Third wave feminist critique

From 2000 onwards, the third wave of critique centred more on post modern and post-structural concerns. Advances in embryonic stem cell research contributed to the shift in the critique with even greater attention being devoted to subjectivity, agency and 'competing' rights of those involved with AR. Some theorists however were still exploring the impacts of pronatalism and the definition of all women in relation to reproductive status; 'one is either a mother, a potential mother, childless, child free or infertile' (Kent 2000, p.105).

Kent (2000) and Maher (2001) maintained the view that AR functioned as another form of patriarchal oppression and both discussed the medicalisation of women's health, notably reproductive health, citing the language and practice of medical science as evidence of systematic oppression. They postulated that AR is another mechanism to reinforce the objectification and 'otherness' of women.

Largely due to its complexity and range of potential impacts, AR remained an attractive site for feminist philosophy; when 'reproduction becomes problematic it provides a lens through which cultural norms, struggle and transformations can be viewed' (Rapp 2001, p.466). In this sense then the role played by predominantly male scientists in AR is typically venerated and amplified, while the women are often less visible, less 'active' participants, AR retains its normative power. This reinforcement of the Aristotelian tradition of male as active, female as passive thus serves as another mechanism to preserve male dominance in a gendered social order (Bourdieu 2001).

Notwithstanding these macro–level concerns, Gore and Lavender (2001) maintained that AR provided women with real reproductive choice and that first wave (and some later) feminists had done women a disservice by using fear to undermine women's choices. However without adequate, accurate information about AR, without greater clinical effectiveness and safety, and with the continued absence of a range of valued life options and social roles for women, real 'choice' remains a fragile concept open to ongoing debate. And without adequate consideration of these core issues, Gore and Lavender's position about choice is difficult to maintain.

With the normalisation of AR and with the increasingly routine use of medical imaging and 'the new transparency of the body', critique of AR continued to explore the dualisms of the biomedical discourse and how this reinforces gender power relations. Along these lines, Lie (2002, pp.393-304) saw AR as a new cultural model for gender relations in that it is a technology that exceeds previous forms because it is so directly enacted on bodies to form new life and to create new stories of procreation. Lie (2002, p.381) argued that reproductive technologies mean that women are 'no longer the creators of children' but rather 'are one of several participants in the process' and that this separation of nature from its unity with the female body had a major influence on cultural understandings of female/male and the hegemony of scientific explanations in Western discourse, declaring 'science as the new father'.

In addition to the routine use of medical imaging technology, the growth in embryonic stem cell research adds further layers to the critique of reproductive technologies. In Smith's (2003) analysis of public discourse regarding access to reproductive

technologies in Australia, the emergent personhood of the foetus was seen as a means to 'discipline the identity of the mother' and to limit access to AR to 'conventional' heterosexual couples. She noted that the debate largely rested on the disembodiment of the foetus and of women and that this fragmented women from their foetuses and obscured foetal dependence on women. The place of medical imaging technology making women's bodies transparent contributed to a further loss of reproductive control for women and increased women's invisibility as active subjects in this context. Smith challenged the basis of hetero-normative discourse in AR and noted that women's rights were often discussed as being in competition with the rights of the unborn. Further, Smith said that women's needs were de-prioritised in favour of those of the unborn (2003, p.80). This critique again exposed the inadequacies of a the biomedical knowledge base founded on individual, competing 'rights' in preference to an alternative knowledge base founded on interrelationships, interdependence and fluid subjectivity, as argued by Shildrick (1997).

The normalisation and marketing of AR reveals terminology, imagery and symbols which often appear to reinforce modernist, Cartesian notions of the body and its processes. Seguin (2001) argued that the linguistic, textual and visual imagery of AR discourse constituted particular political positions for various players in the political debate and that the separation of science from its social context keeps science distant from criticism. The commercialised, metaphoric language used in AR (e.g. *banking* of gametes and embryos, sperm *deposits*, *products* of conception, *extraction/collection* of eggs, etc) also serves to dehumanise and fragment the process of reproduction and to confirm the transformation of humans into scientific work objects (Lie 2002; Sharp 2000). Sharp (2000, p.7) also noted that women's bodies 'are frequently prized for their reproductive potential, rendering them especially vulnerable to commoditisation'. The woman's body especially is perceived as the 'body-for-others, constantly exposed to the objectification performed by the gaze and the discourse of others' (Bourdieu 2001, p.63).

Some of the most common visual symbols used in AR: one sperm penetrating an ovum in a glass dish; a needle puncturing an ovum wall, presumably to insert sperm directly

into the ovum, reinforce notions of fragmentation, masculine domination and feminine passivity in the process of reproduction. The ovum is represented as static and vulnerable to penetration and this serves to legitimise domination by 'embedding it in a biological nature that is itself a naturalised social construction' (Bourdieu 2001, p.23). This symbolic violence is not, however, necessarily enacted at 'the level of conscious intentions' (Bourdieu 2001, p.59) but nonetheless performs a key role in the discourse of AR. That the union of ovum and sperm is but one event, albeit an important one, in a complex and often little understood range of processes that result in a successful pregnancy, is not highlighted. Most of the other necessary processes occur in the 'privacy' of a woman's body and are relatively unacknowledged. This reinforces the 'naturalness' and importance of the 'public' AR process of fertilisation, *in vitro*, and reinforces the invisibility and private nature of women's procreative capacities. It separates women from procreative power and reproductive capacity, citing male-dominated science as a better method (Dominelli, 2002; Lie 2002; Corea 1988). Thus, technological intervention in procreation via AR is privileged. Women's bodies become detached from the process, as if reproduction was itself disembodied rather than it being a process dependent on interrelationships and cooperative exchange.

Also in this third wave critique, Rapp (2004) continued to argue that social inequities are exacerbated in assisted reproduction and that access was still clearly restricted along class and race lines, particularly in the highly privatised service provision context in the United States of America. Arguably this stratification also extends to geographic stratification in that most clinics are located in metropolitan areas, leaving non-metropolitan people at a disadvantage. Rapp asserted that AR in the twenty-first century still operated 'along familiar lines' characterised by a lack of informed consent and a lack of women-centredness. She noted the emergence of stem cell research and the persistent 'pharmaceuticalisation' of reproductive technologies where if things are not profitable, they are not developed. She also criticised the lack of systematic regulation of AR and argues that self-regulation is 'like the fox watching the chicken coop'. Rapp reiterated the need for women's aspirations to be central to AR and for ongoing consideration of the benefits and costs of the technology in the broadest sense. Some other third wave critics repeated the call for increased fertility education

aimed at reducing involuntary childlessness due to age-related and biophysical causes thereby reducing overall reliance on reproductive technologies (e.g. Inhorn 2003b). This direction while certainly not new still seemed to struggle in the face of effective marketing of assisted conception services, the power of the biomedical lobby groups and the ongoing biomedical dominance of the discourse.

Throsby (2004, p.163) made women and their partners central to her qualitative research into experiences of AR and her approach to the field did not simply cast AR as 'bad' and women as 'good' or 'victims'; instead, she argued that the technology has many meanings and none are absolute and that service users are not passive in the process but that they are actively engaged. Throsby identified some key themes in how service users approach AR; normalising, coping, taking responsibility, managing visibility and seeking resolution. For service users, she argued, it is necessary to normalise infertility as a disease and childlessness as non-normative in order to accept AR as a treatment and to engage with the technology; these findings echo Klein's research in the late 1980s. Throsby also highlighted the disjuncture between the persistent public perception of AR as a successful, accessible solution and the actual experience of AR. Throsby said that the failure of AR is the most common experience and that people having experienced this failure, faced the challenging task of resolving themselves to childlessness to 'ongoing in-between-ness', in a context where choice is limited and parenthood, especially motherhood, is the norm.

The notion of choice and maternal citizenship in Australia was considered by Kevin (2005b) who maintained that there had been a conservative shift in policies fuelled by 'fertility panic' about declining birth rates and delayed parenting. Government policies and regulatory requirements in this country, she claimed, serve to limit the range of options available and to restrict unconventional life choices for women. In her analysis of policies relating to reproduction, she argued that AR was still serving to maintain traditional gender relations and power hierarchies, as argued by the first wave of feminist critics. To remedy this policy bias, Kevin (2005a, p.11) said that it is necessary to include the narratives of service users in political debates, decision-making and

regulation of AR and that: 'in slowing down to listen we might achieve something approximating genuine progress'.

An example of a research project that did 'slow down to listen' to service users is Thompson's (2005) ethnographic research conducted in clinics in the United States of America. Thompson explored the 'ontological choreography' of AR and methodically traced the changes in how kinship ties and possibilities are negotiated by service users and clinicians alike. She said that what appears to be 'messy' in terms of the legal, ethical, relational, emotional, financial and political aspects of AR is 'actually deftly balanced' choreography by all participants involved. An important contribution of this work is its reconceptualising of women as active participants in AR in that they are aware of and co-operate in the biomedical objectification of their own bodies in order to achieve their goal. Haraway described Thompson's contribution as a move away from the 'scolding critique' of 'caricatured feminist theory' and to a more transformative account of women's agency in AR and of all the people involved in AR experiences (Haraway 2000, p.5).

One criticism of this work is that Thompson adopts the medicalised language of 'treatment', 'patient', etc, throughout her account of the project. The persistent use of this medicalised terminology leaves the biomedical paradigm fairly much intact. And while the concept of ontological choreography is useful in mapping the redefinitions and normalisation processes used by those service users and clinicians, it is less successful in re-envisioning AR. The 'dance' metaphor could in fact be seen as reinforcing the secondary status of women with the lead dance roles going to the medical practitioners, and women and their partners, at best, being members of the chorus line.

Gupta (2006, p.35) took a wavering view of women's agency in relation to AR. She discussed global fertility tourism and gamete trading and said that for some women, especially those with socioeconomic power, AR may well provide increased options, agency and self-control but for others, especially those in lower socioeconomic contexts experiencing intersectional disadvantage, it results in reproduction being expropriated and controlled by externalities. Gupta identified a need for more

research into local and contextual knowledge and realities in relation to AR and urged that such research be based on concern for women's wellbeing and health and for it to 'go beyond narrow individualism' to 'protect women's self-respect and human dignity', a call for 'continuities with earlier feminist problematisations of reproductive politics' reinforced by Gerodetti and Mottier (2009, p.148).

An example of research that moved beyond this individualistic and linear focus is McCarthy (2008, pp.322-324) who claimed that most psychosocial research into the impacts of AR in the last twenty-five years has been limited to the active-use phase of the AR experience and that very little has been done to explore the post-AR experiences of service users, especially after unsuccessful AR. Her phenomenological research conducted in the USA identified several themes in women's experiences after unsuccessful AR, including a re-envisioning of oneself in life's context, dealing with the ongoing isolation and grief of involuntary childlessness and choosing to create a new, different kind of life story for a meaningful future. Many of the participants in McCarthy's research described the care they received from AR clinic clinicians and administrative staff as 'impersonal and frequently insensitive' and an 'almost exclusive attention to the technology'. This experiential knowledge mirrors first and second feminist research findings and points to the need for ongoing critique and effort to enact real changes in the quality, range and level of service provided by clinics.

Along with these persistent concerns for women's wellbeing, other developments in reproductive technologies and the growing emphasis on embryonic stem cell research in the new millennium have led to further shifts in the dominant discourse, still largely to the exclusion of women's interests. Kirejczyk (2008, p.389) described the shift in discourse as a shift from reproduction and embryos for reproductive purposes to a focus on embryos as items for research, particularly stem cell research. The views and position of women, she argued, rarely rate a mention, and women in general are not respected, except in terms of the scarcity of ova. Further she argued that embryos are now increasingly seen as independent entities and that the fate of 'spare' embryos has been enticingly linked to promises of miracle cures for a range of diseases – 'the quality of the promises being made is not assessed' and that other research priorities

would better serve the interests of women. This shift in emphasis from embryos for procreation to embryos for research, Kirejczyk said, also placed a 'moral imperative' on women to donate ova and 'spare' embryos despite the risks involved and regardless of the meanings attached to embryos by women. She insisted that there needed to be an urgent broad debate about embryonic and reproductive research so that the direction this research takes is not decided by 'other interested parties' in the absence of women's voices in the debate.

Feminist critique of AR has been productive and consistent over the last three decades although some argue that feminist critique has at times failed to adequately acknowledge the experiences of involuntary childlessness at a corporeal level (e.g. Valentine 2008). Nordqvist (2008, p.288) also criticised feminist theory being partly responsible for perpetuating a hetero-normative bias in analysing and theorising AR, marginalising lesbian women in 'the procreative imaginaries of reproductive technologies' both in terms of active users of the technology and as partners.

Major themes from the literature review

> *Pay attention to what is missing... Researchers can ask what is not being measured in a debate...they can ask whether the deeply held assumptions of a line of thinking actually hold up...testing the logic of a conventional argument* (Sprague 2005, p.187).

Following Sprague's advice, what then is missing from the debate? What is missing or under-represented or undervalued in current knowledge about assisted reproduction in Australia? Women's voices are still either missing or only softly heard in the debate, rural women's voices, particularly. And something is certainly amiss in the debate when a major 'independent' government review of assisted reproductive technology asserted that there was a 'scarcity' of psychosocial, ethical and legal literature on AR (ARTRC 2006, p.40) and did not cite a single item of social research in their report, despite one of their own review committee members having presided over a substantial research project (Arndt 2005). This implies that the contributions of a large amount of national and international social research related to AR is not recognised or valued by AR power figures in Australia and the disturbing questions are: why should

this be the case? What purposes does it serve? And whose interests are being preserved by the *status quo*?

Despite first wave feminist resistance and other sustained criticism of reproductive technology, it has become a generally accepted part of the reproductive health landscape and even in the face of sustained and extended criticism, its place seems secure. But 'accepting the techno-present' need not mean 'falling victim to its brutality' (Braidotti 2006, p.206). There seems to be an opportunity to more effectively engage with and ideally to evolve the science of AR, rather than to perpetuate what Haraway described as 'the alienation' of AR (Haraway 2000, p.5). Is it possible to engage with practitioners who might not share an interest in such engagement? Is it possible to force evolution upon the biomedical paradigm? For the dominant discourse of AR to be loosened and reconfigured, would be one positive step, but would that necessarily make it any safer or clinically effective for consumers who use its services? Are the alternatives to give up the critique or keep trying to re-envision AR?

Important questions need to be answered convincingly about assisted reproduction, especially in relation to the short term and long term implications for both women and children. It is also important to continue to find the most effective ways to target government and private funds in relation to reproductive options, and to advocate for more research into infertility, prevention and fertility preservation. It is vital that AR's clinical effectiveness improve for it to be considered a reliable, safe reproductive choice. At a broader epistemological level, the task of re-envisioning AR into a more permeable knowledge base is an ongoing process. The task is most certainly to re-envision, not simply to include or incorporate women into the existing framework as curious additions or to placate critics of the biomedical approach. As Irigaray (1985b, p.78) stated 'women do not aspire simply to be men's equals in knowledge' or to be 'the philosopher's wife'. To simply add women to the existing situation would be inadequate and might only serve to reinforce the very thing that disenfranchises them; this is at the heart of the epistemological issues in assisted reproduction.

The predominance of the biomedical approach to reproductive technology individualises what is essentially a social decision that occurs in a social context;

decisions about reproduction have a broader impact. There is a need to develop and validate a broader socio-political discourse to render the implications of AR open for discussion and for service users to be included as pivotal in such discussion. For AR to be a humane, holistic and responsive option, experiential and practical knowledge is required, in addition to theoretical knowledge (Langdridge & Blyth 2001) and because 'the objective of providing children to the involuntarily childless [is] not… simply a quest for technical excellence' (Blyth 1999a, p.737), more in-depth, qualitative research is required to ensure quality of service provision and to broaden the discourse.

Given the attention and positive regard that AR commands in popular culture and the demanding nature of the procedures and as part of the re-envisioning process, it is vital that more is heard from those who have experienced AR. Research is needed on the experiences of women, their partners and families and on the nature of reproductive decision-making. Given that much of the qualitative research into Australian women's experiences of reproductive technology was done in the 1980s, and in light of the expansion in the number of AR clinics in metropolitan and non-metropolitan areas since then, it is timely to explore what, if anything, has changed for service users in the new millennium. Because much of the previous research was based on conventional models of service delivery, how do different models of service delivery impact on clients in outreach or satellite clinics? As most satellite clinics are in non-metropolitan locations, how does this context impact on service users? Are there particular issues for women based in rural and regional areas? Since psychosocial support before, during and after AR has been identified as an important element of AR service provision, exploration of service users' support needs, the accessibility of psychosocial support and service users' views on the effectiveness of support that was available would also be useful.

This research contributes to re-envisioning the discourse of AR by actively seeking the input of women who have used reproductive technology, specifically women in non-metropolitan locations, and exploring their experiences and support needs. The next chapter details the project's conceptual framework and the subsequent chapter

presents how the project was conducted, including the recruitment of research participants as well as the methodology underpinning the project.

Chapter 5 - The conceptual framework

One of the major themes emerging from the literature review is that the dominance of the biomedical paradigm in assisted reproduction persists despite several decades of feminist (and other) theory-building and critique. It is argued that over reliance on this paradigm as a knowledge base in the context of reproduction is inadequate and inaccurate and that the dominance cannot be justified in ontological and epistemological terms. The major deficits in the biomedical paradigm stem from its foundation in dualisms and the consequent assumptions about the subjectivity and agency of individuals. It is argued that these deficits are so fundamental that there is a need to envision a more inclusive, dynamic knowledge base to more adequately represent the realm of assisted reproduction.

This chapter presents this study's conceptual framework and demonstrates how it holistically and effectively captures the complexity and interrelationships of assisted reproduction when compared with traditional biomedical, linear, individualised accounts. The framework challenges the nature of knowledge in the context of assisted reproduction and *inter alia* draws on the work of Charis Thompson, Donna Haraway, Rosi Braidotti and Margrit Shildrick. This approach goes beyond merely incorporating women's experiences into the existing dominant paradigm; its aim is to de-territorialise knowledge and to contribute to a knowledge base that is more transformative and emancipatory for all involved in AR (Braidotti 2005; Harding 1991; Shildrick 1997). Before presenting this conceptual framework, it is useful to consider the limitations of the biomedical paradigm in more detail.

Some limitations of the biomedical paradigm

'Biomedicine' as 'a derivative category of Western science more generally' is comprised of three ontological spheres: empirical, interpretive and conceptual. These spheres represent the 'symbolic-cultural' nature of biomedicine and its power in Western knowledge. The biomedical discourse itself conceals this ideological agenda beneath a cloak of 'scientific objectivity' and detachment (Baronov 2008, p.235). Rather than being detached and neutral, feminism has been very successful in exposing the ways in which biomedicine constructs, reflects and perpetuates

established power relations in society, particularly the male-female gender hierarchy (Harding 1991; Lupton 2004; Shildrick 2004). The illusion of neutrality - which Haraway (1988) refers to as 'knowledge from nowhere' and the 'god trick' - is pervasive in modern Western science and it depends on Cartesian dualisms, especially the mind-body split. This binary ensures that there is an ontological gap between rationality and embodiment (Braidotti 1991). This and other key dichotomies like culture/nature, male/female are also hierarchical and without exception, women are cast as 'other' in a subordinate position in relation to men.

At the ontological level the subject in traditional science is disembodied, rational, unitary and most definitely male, leaving women 'ontologically out of order' (Braidotti 1991). The profound androcentrism of the disembodied subject coupled with traditional science's penchant for universalism leads to a knowledge base predicated on epistemic oversights and exclusions; one that fails to acknowledge its context or to account for sexual difference or to adequately theorise human bodies and bodily experiences.

Human bodies in biomedicine are typically attributed with mechanistic qualities, depersonalised as objects to be acted upon rather than as active agents in their own right. Their various parts are disaggregated and approached in a specialised, fragmented manner with limited regard for interconnectedness and inter-relationships. Faulty parts and dysfunctions are assessed, diagnosed, treated and (ideally) cured in the linear medical model. The broader context of bodies and their parts is often not given adequate consideration. Whole body processes are broken down into their component parts, sometimes into a seemingly disconnected set of discontinuous steps; a perspective that swaps 'totality for the parts that comprise it' (Braidotti 1994, p.48). Bodies are reduced to sameness and commonness by this dismembering. With sameness and standardisation, differences are not recognised and crucially sexual differences are reconfigured with women's bodies being typically defined as faulty and problematic. The process of human reproduction brings these ontological and epistemological inadequacies into sharp focus.

Reproduction is where difference between the sexes is most defined and obvious and, paradoxically, women's capacities and power most apparent yet devalued in conventional discourse. Biomedicine has long sought to medicalise and control human reproduction and assisted reproduction is another example in a long line of biomedical endeavours with similar effects. There is much feminist literature on the medicalisation of pregnancy, childbirth, breastfeeding, child care and gynaecology; on the general dislocation of motherhood and attempts to deny that the origins of all life are in a woman's body (Braidotti 1994).

Given this ontological foundation, epistemic privilege is accorded to a particular form of masculine perspective. The perspectives of 'others' are either excluded entirely, incorporated as pathological and atypical according to the male-as-standard yardstick, and/or have interpretive frameworks imposed on them regardless of fit. This 'epistemic imperialism' and 'epistemic indolence' along with the monological habits of phallocentrism compromise the completeness and the validity of the biomedical paradigm to fully account for a range of human experiences (Braidotti 1991, p.190; Braidotti 1994). This foundational criticism also indicates that alternative paradigms pose deep threats to social order if the gendered nature of science is exposed and transcended (Harding 1986).

These criticisms of traditional science and biomedicine do not imply that systematic enquiry is to be abandoned altogether; indeed a more complex and inclusive post-conventional ontological foundation would improve the quality of knowledge. To this end Hartsock (1985) urges us to criticise 'bad science' as well as 'science as usual' in all its partiality, gender bias and exclusion and to pursue epistemologies based on interrelationships and interdependence.

An alternative, post-conventional paradigm: Key theorists and concepts

In light of the criticisms of biomedicine, an alternative paradigm needs to:

- conceptualise subjectivity as embodied, active, interconnected and interdependent;
- validate experiential knowledge; and,

- acknowledge the broader context from which knowledge originates as well as its broader social implications.

The work of Luce Irigaray (1984; 1985a) is a useful basis for developing such an alternative paradigm. Irigaray's overall aim is to disrupt the male mode of knowledge and its universalism and oppositional stance – to reject the singular, male vantage point in the creation of knowledge. She wishes to make *difference* a key part in the ontology of an alternative paradigm and clearly articulates that difference must be regarded as difference *between females and males*, not difference *from the male* – the latter position would maintain the male as standard and women as 'non-men'. Exchange between humans is a key element of Irigaray's philosophy.

Of particular interest is Irigaray's argument that there is a need for women to reclaim reproductive capacity and power and to develop a feminist genealogy to recognise and validate relationships between women and their mothers. She also argues that current forms of knowledge dominant in traditional biomedicine offer a mechanistic view of human bodies and importantly that this view is inadequate to account for the sociality between humans, women and foetuses in particular. Irigaray advocates for embodied identity and ethics based on lived experience and she recommends empirical studies to form the basis of a new paradigm to adequately account for 'the sex which is not one' (Irigaray 1985b).

Similarly, Rosi Braidotti (1991; 1994; 2005; 2006) argues that the patriarchal theoretical system fails to recognise interconnections and the fluidity of subjects – her concept of 'the nomadic subject' (Braidotti 1994). Braidotti's thesis is that in sexualising discourse, the false universalism of theoretical statements and the ontological frailty of traditional scientific discourse is exposed (Braidotti 1991). Braidotti's theory of embodiment is significant. It suggests that women's bodies are not reduced to biologically determined destiny; bodies experience the world and its complexity in multiple and sometimes contradictory ways. As with Irigaray, Braidotti identifies the centrality of human reproduction and women's procreative power. In the context of the developments in reproductive technology, Braidotti also identifies biotechnology as an especially powerful tool in the mastery of reproduction and a key

element in maintaining masculine hegemony; 'no area of contemporary technological development is more crucial to the construction of gender than the new reproductive technologies' (Braidotti 1991, p.79).

Braidotti identifies the need for feminists to effect epistemological, political and ethical transformation in the context of AR, arguing that AR represents an important opportunity for such transformation and that it is a risk but not necessarily a *fait accompli* that traditional science will maintain its dominance in this domain (Braidotti 2005). This is a key issue in relation to AR because reproductive technologies offer many challenges to conventional modes of thinking and ways of being and they disrupt many conventional kinship patterns. For Braidotti (2005, pp.171-178) two possibilities emerge for women from AR.

1. If the traditional biomedical paradigm continues to dominate, there is a risk of women (and men and embryos) becoming *disposable commodities* in the context of AR and for generative capacities to be exploited for commercial gain;
2. If an alternative paradigm acknowledging women as *decisive agents* in AR can gain traction, the interests of women and embryos and humankind are more likely to be safeguarded.

This project makes a contribution to the second option.

Charis Thompson, Margrit Shildrick and Donna Haraway, also identify similar opportunities as well as risks in relation to AR. Thompson (2005, p.275) also sees that AR is not inherently dehumanising and that it provides women and their partners with opportunities to pursue procreative intent and to potentially 'restore life course'. She postulates that women actively participate in the rituals, artefacts and patterns of objectification inherent in AR processes in order to achieve the desired transformation. This intentional subordination is not undertaken to comply with the physician, but is made to achieve the desired goal. The physician is one link in a chain of actors required to achieve the goal. In addition to the medical practitioners, nursing, laboratory and other clinic staff also participate in this chain of interactions in order to achieve the aims of AR. If however objectification is imposed rather than negotiated, Thompson

argues that this denial of women's control is highly condemned by service users and clinic staff. This is Thompson's concept of 'ontological choreography'.

Ontologically, Thompson says that women in AR have multiple positions; they often juggle paid work and other commitments as they engage with AR; they are at times 'the patient' in the waiting room; they are at times reduced to body parts – to ovaries, tubes, follicles on a screen, and at other times they are anaesthetised bodies. While ontological choreography is useful to conceptualise the actual and potential interrelationships and interactions between service users and service providers, it is less effective in disrupting the traditional biomedical paradigm.

For choreography to be a wholly effective metaphor, all people involved in the process presumably need to be aware that they are part of a troupe of dancers, each experiencing some time in the spotlight. If some individuals perceive themselves as solo performers in the spotlight, and if they do not acknowledge their dance partners (or worse still, if they keep stepping on her toes with no apology) then the notion of choreography is limited to their own individual dance steps, others are merely props to their performance and therefore not recognised as integral parts of a unified effort, as implied by Thompson's concept.

Ontological choreography is also an appealing concept because it implies dynamism, exchange and cooperation. Because of the sustained domination of the biomedical paradigm, ontological choreography is rendered less effective to conceptualise how AR is currently delivered in many clinics and how it is experienced by many women. Ontological choreography is also useful in conceptualising the fluidity of subjectivity and the possibility of co-existing object and subject status. It becomes problematic if the dominant paradigm is based on object status and disembodied subjectivity, and if that paradigm is incapable of accommodating fluid subjectivity.

Thompson's ontological choreography is useful but it does not move far enough beyond the medical paradigm to effectively disrupt it. A disappointing feature of Thompson's work is her consistent reference to women as 'patients' and to AR procedures as 'treatments'. The adoption of a medicalised lexicon is unfortunate in that it reinforces the overall ascendency of traditional biomedicine and its symbols.

This practice should be resisted, according to Irigaray, Shildrick and others. A thorough and consistent re-imagining of AR is needed and Shildrick's work would take us further towards a post-conventional knowledge base.

Shildrick (1997; 2002; 2004; 2006) considers the biomedical model in the context of AR in terms of subjectivity as well as bioethics, providing a more comprehensive alternative paradigm than Thompson's. Shildrick engages with Irigaray's notion of dual subjectivity to envisage how 'fluid subjectivity' could form the basis for a post-conventional ethics and for a more adequate AR knowledge base in biomedicine (Shildrick 1997). Shildrick criticises conventional bioethics for being 'curiously disembodied' and for taking the 'sovereign subject' as its ontological basis (Shildrick 2004, p.149). She identifies a need for increased recognition of the mutuality of relationships in the biomedical encounter and for more effective acknowledgement of the contexts in which biomedicine and its disembodied subject is immersed. Of particular interest to this study is her insistence that reproductive technologies strain conventional ethical paradigms.

Shildrick says that traditional biomedicine relies on the Cartesian erasure of corporeality and that this 'horror of fluidity' is 'characteristically male'. Feminist notions of dual subjectivity are therefore a major threat to the 'certainty of closure' provided by the singular subject (Shildrick 2006, pp.40-42). Like Thompson, Shildrick emphasises the mutuality of the biomedical encounter and identifies traditional science as a cultural representation in itself especially in the absence of women as ontological agents.

For Shildrick, as for Braidotti, Thompson and Haraway (and others) the power of AR to disrupt and expose many established binaries is, controlled, paradoxically, by the tighter imposition of the traditional biomedical model. It seems that the more threatening and plentiful the disruptions, the greater the insistence on traditional biomedicine and its sovereign, disembodied subject. This highlights the central task for feminism in this context – to challenge and change the very foundations of traditional Western knowledge starting from the ontological level through to the epistemological and methodological levels. Without redressing the inevitable philosophical

disadvantage of women within the traditional scientific paradigm there can be no effective epistemological transformation.

Shildrick therefore insists on the need to 'refuse the comforting refuge of broad categories and fixed unidirectional vision' and to 'deterritorialise' knowledge to include dynamic, fluid ways of knowing (Shildrick 1997, p.3). Fluidity also implies that there is no unified category of 'woman' but rather multiple, fluid possibilities for women, unified by a specific body form. Like Braidotti's nomadic subjectivity, fluid subjectivity acknowledges that experiences of a phenomenon will be contextual, variable and sometimes contradictory and that universalism is as inadequate as it is unattainable.

Shildrick's post-conventional bioethics casts all involved in AR as equal moral agents, thereby addressing some of the limitations of Thompson's concept of ontological choreography. Shildrick thoroughly rejects the biomedical model and its fragmentation of women into a set of functional norms and body parts with no personhood and she refuses to label women as 'patients'. She says that the female role in reproduction has traditionally been denied or at least downplayed, from Aristotle through to Judeo-Christian creation stories and Hartsoeker's (1694) idea that fully formed embryos are contained in men's sperm and that women are simply incubators of these 'animalcules'. She states that:

> *...At best, the mother's body – and this is an idea which has been recirculated throughout medical history – is just a container, a bounded space within which certain processes occur* (Shildrick 1997, p. 25).

If women are pathologised in this way, as objects for the clinical gaze (Foucault 2003), they are also often thereby silenced. Traditional medicine is left to practice on bodies as universalised, standardised objects, rather than as unique socially situated individuals. Thus it becomes sufficient to treat 'patients' with 'technical proficiency rather than with care and concern' (Shildrick 1997, pp.76-77).

Shildrick argues that the medical model obscures the transactional nature of medical encounters as well as obscuring women as intentional, full moral agents. An important step in re-envisioning AR, then, is to reaffirm embodiment as ontologically foundational and via phenomenological inquiry, to seek experiential, 'situated'

knowledge as a basis for this restoration and to assert that 'women are not simply passive victims in the face of scientific developments' (Shildrick 1997, p.210).

Shildrick, like Donna Haraway, emphasises that the deconstruction of traditional science does not equate with its destruction; there is clearly a need for systematic, rigorous scientific knowledge on a range of matters and its contributions deserve proper recognition as *part of* a broader range of knowledge. The persistent dominance of the traditional scientific paradigm has resulted in this form of knowledge being privileged and this need not be the case. Loosening up knowledge to legitimate other ways of knowing would promote richer, more complex types of knowledge being recognised in various contexts – 'successor science', as advocated by Harding (2004). And also like Haraway, Shildrick sees AR as a particularly ripe context for loosening the grip of traditional science and for the development of a post-conventional paradigm.

Haraway (1988; 1989; 1997; 2000; 2004a; 2004b) is considered a 'major foundation' for post-conventional ethics (Shildrick 2004). She provides a critical but not a rejectionist approach to traditional science as she engages with techno-science to envision a more comprehensive science based on collectivism rather than individualism (Haraway 2004b; Valentine 2008). Haraway (2004a, pp.23-35) advocates engagement with biotechnology as she sees it as a crucial part of our existence, 're-crafting our bodies' and with 'serious potential for changing the rules of the game' – particularly in relation to 'phallocentric origin stories' and persistent dualisms. In this way, Haraway analyses science more comprehensively than does Foucault (2003) with his notion of bio-power. It is acknowledged that Foucault makes a useful contribution in terms of the situated nature of traditional science and in terms of the body as a site of power, but he fails to consider sexual difference adequately and to account for issues, like procreative capacity, closely linked with female sexuality and he fails to acknowledge the ontological disadvantage of women in traditional biomedicine (Braidotti 1991).

Haraway's aim is to avoid what she calls 'the dismembering cannibalism' of Cartesian epistemology and to deliver a transformative, complex system of knowledge based on a radical subversion of the traditional singular subject. This singular subject, she says,

results in women being devalued in Western logos, as disappearing from the field as visible social agents, because of 'their bodies' troubling talent for making other bodies' (Haraway 1989, p.39; Braidotti 2006). This statement deftly captures the central challenge that women's reproductive capacities pose to traditional ideas about ontology and underscores why reproduction continues to be such a focus for feminist theory.

For Haraway (1991; 1997; 2004a), subjectivity is inter-relational, non-linear and non-fixed. She uses various images to describe this conceptualisation of subjectivity: 'the cyborg'; 'onco-mouse'; companion species. As with Shildrick's 'leaky bodies' (1997) and Braidotti's 'nomadic subjects' (1994), this form of ontology captures multiple ways of being and serves to undermine the power of the bounded unitary subject and to open-up epistemological possibilities. Embodiment and corporeality are central in these theories and bodies are recognised as active and dynamic, and not just as cultural texts in discourse. This is the major reason why Judith Butler's concept of performativity has not been used, although it is acknowledged that Butler has much to offer in her rejection of the gender/sex binary and in her critique of the epistemic privilege accorded to some bodies in traditional science (Butler 1990 & 1993; Kevin 1999; Webster 2002b).

Another key contribution from Haraway (2004b) is her concept of situated knowledge and her rejection of traditional science's 'knowledge from nowhere' and 'the god trick'. Situated knowledge then is the recognition that knowledge is grounded, embodied, contextual, partial, complex and based on engagement and interconnections rather than on disembodiment and transcendence. She describes contexts as 'material webs of human and non-human actors' (Haraway 1997, p.116). This is especially relevant to the context of reproductive technology whereby human and non-human actors (medical practitioners, clinic staff, laboratory equipment, syringes, for example) are part of a complex system working toward a specific outcome. These interactions are regarded by Haraway as new forms of kinship which create 'affectionate ties' to human as well as non-human others (Haraway 1997).

Drawing mostly on the work of Braidotti, Shildrick and Haraway and with reference to Irigaray and Thompson, the key elements of the conceptual framework for this study can be summarised as follows:

- In terms of ontology, this study resists disembodied, singular, bound subjectivity and subscribes to an ontology whereby embodiment, interrelationships, mutuality, fluidity and interdependence are central.

- In terms of epistemology, this study acknowledges the value of many forms of knowledge, but resists the dominance of traditional science and its claims to universalism especially in the context of assisted reproduction. It subscribes to an epistemology that is contextualised, experiential, complex and provisional; one that captures a range of women's lived experiences of AR in a rich and variable way. There is no pretence that this experiential knowledge forms some sort of categorical knowledge for all women. Rather it is argued that there is value in considering the various experiences of a phenomenon including commonalities, differences, quirkiness and contradictions and that the shared body form, desired life path (in this instance parenthood) and capacities of the situated knowers provides a unifying thread.

Enacting a post-conventional paradigm

This study's conceptual framework has been constructed in the hope that it will build on feminist theory relating to assisted reproduction in three ways (as advocated by Davis 2007) by contributing to:

1. the *reconceptualisation of the body*;
2. the documentation and exploration of the *embodied experiences* of service users; and,
3. the enactment of *epistemic agency* to women who have engaged with AR.

Bodies in this study are not disconnected or unitary and nor are they represented as one element of the mind-body binary so pervasive in traditional scientific paradigm. The bodies in this study are *reconceptualised* as corporeal, biological bodies engaged in constant interrelationships and connections with others; they are more than a cultural text or site. These bodies feel pain, pleasure, think, speak, laugh, interact and connect

with others in mutual exchange. In this way, this study will help to reduce the 'silence of feminism on flesh and blood bodies' and to document experiential, situated knowledge of AR in an effort to disrupt the dominant knowledge paradigm (Davis 2007, p.54).

In this research the *embodied experiences* of AR service users are sought via qualitative methodology and the phenomenological basis of this inquiry is crucial to the aims of the project in that women are valued as embodied subjects with situated knowledge of AR. These women as service users, as situated knowers, interpret, reflect on and re-work their experiences of AR and as such their knowledge is 'epistemologically indispensable' as a central starting point for theory (Davis 2007, p.57). Seeking women's knowledge in this way ensures that *epistemic agency is* afforded to the women as participants with a resource to contribute to the knowledge base of AR.

In terms of methodology, if the aim is to tap into experiential knowledge of AR, then it is logical that such a qualitative approach is taken as it affords maximum flexibility for self-selected research participants to tell their stories. This study's methodology is detailed in the next chapter.

Chapter 6 - The research process

...sentient, embodied, experiential knowing as a resource for unmasking the universalist pretensions of science and for providing the basis for an alternative, critical epistemology, which would be grounded in the material reality of women's lives (Davis 2007, p.53).

The preceding chapters have established that the dominant discursive base of assisted reproduction is biomedical, androcentric and dualist, that biomedical knowledge is not 'knowledge from nowhere' and that it has an 'unconfessed bias' (Diaz 2002, pp.249 & 254). There is a need to develop knowledge from a range of different social positions so as not to perpetuate the hegemonic view (Sprague 2005) and to act as a 'modest witness' to the practices of AR (Haraway 1997). While the voices of women have been sought at times and used as means of contesting the dominant discursive and power bases of AR, phenomenological enquiry into assisted reproduction has arguably been of limited influence to date and the dominant discourse remains biomedical in essence. The creation of a more inclusive, integrated understanding of AR is very much a work in progress and this project aims to contribute to this important effort to de-territorialise knowledge (Shildrick 1997).

This study is phenomenological in that it seeks information directly from non-metropolitan women who have experienced assisted reproduction. The importance of gaining information from these women is twofold; contemporary information on lived experiences of AR in Australia is a worthy project given that the bulk of qualitative, feminist social research was done in the late 1980s and early 1990s and the significant changes to service delivery networks and technological developments since then. In addition, specific information from women living outside metropolitan areas is under-researched. Given the locational disadvantages faced by rural and regional Australians, service delivery in this context is likely to pose additional challenges and impacts. Before focusing on methodology, the research paradigm underpinning the research process is examined in finer detail to firmly establish the synthesis between the ontological, epistemological and methodological framework.

Phenomenology is a philosophy first described by Husserl in the 1960s (Husserl 1999) as an attempt to explore the lived experiences of humans. It is also an approach and a

method (Morse 1994). Husserl advocated a transcendental approach to phenomenology based on the research participant's self reflection on their experiences as the basis of knowledge of the world as it is, resulting in a rich description of the experiential context of ordinary life. He required researchers to 'bracket' their own views and presuppositions so that the research participants' accounts could be described and analysed as faithfully as possible (Husserl 1999; Morse 1994). It is mainly on this aspect of Husserl's transcendental phenomenology that Heidegger's critique rests. Heidegger (1975) argued that the researcher's presuppositions cannot be eliminated or suspended and he proposed a hermeneutic-interpretive phenomenology that explicitly recognises the researcher's views (Morse 1994). This project subscribes to an interpretive phenomenology more akin to the ideas of Heidegger than to the descriptive phenomenology of Husserl.

Heidegger also wished to expose the limitations of a strictly Cartesian, dualist approach (Heidegger 1975; Kellett 1997) and in this sense Heidegger's philosophy is particularly relevant to this study in that AR is dominated by dualism and its concomitant objectification and distinction between subject and object. The central concepts of Heideggerian philosophy are that we are interdependent on others and that the sense we make of the world is based on reciprocity and on every day practices and patterns of interaction. He argues that we have a heightened awareness of these patterns when we are perturbed by something unusual and that we then adapt our perceptions and interactions accordingly at an ontological level (Conroy 2003). Existence is therefore temporal in that the past, the present and the future are elements in our way of being in the world at any time. Heidegger referred to this as historicity; we are born into a world where patterns of interaction and meaning are established and we interact with this past and with our experiences of the present and we project what we hope, and plan for the future. This non-static ontology is the basis for the hermeneutic spiral of interpretation in that there are many ways of understanding the world, many intersecting stories that contribute to knowledge over time and a reciprocity and interdependence of all actors in this spiralling process.

Thus it is important to acknowledge the researcher's 'foregrounding' (historicity) as part of the research process and to acknowledge the reciprocity of the researcher-participant relationship in the research process. To this end some contextual information about the researcher and the women who participated in this study has been included in the introduction and Chapter Seven.

This research documents and modestly witnesses, a particular group of women's experiences with assisted reproduction and contributes to the body of feminist post-structural, phenomenological research undertaken with the intention of broadening our overall understanding of assisted reproduction. It needs to be stressed that the aim of disrupting the dominance of the biomedical discourse in this context does not equate with its destruction or its exclusion. On the contrary, the reframing of knowledge in the field of AR via the inclusion of service-user' voices aims to broaden the range of epistemological reference points and to add to the richness of understanding of this phenomenon. This is in line with Haraway's central arguments in her *Cyborg Manifesto*; namely that seeking a universal theory is 'a major mistake' and likewise, that demonising technology is pointless. She argues that there is a need for reconstructing and recognising the connectedness between science and social relations (Haraway 2004a). Knowledge from a positivist perspective has an important place in the scheme of things, but it is not the *only* type of worthwhile knowledge and its place is not *everywhere*; there is a need for a broader, more holistic knowledge base in many areas of human endeavour, including AR.

This research also uncovers and critiques the foundations of the biomedical discourse, its biases and inadequacies and offers a more complex and inclusive interpretive framework in which a range of understandings and experiences of AR are validated. The claim that this research contributes to reconstructed knowledge predicated on a more fluid epistemology is based on the notion that science is inextricably embedded in its social milieu and that this social connectedness needs to be explicitly reconnected otherwise the current knowledge base of AR is on a foundation which is far too narrow and 'gynopic' (Reinharz 1988, cited in Diaz 2002). It could be argued

that much of the discontent felt by AR service users can be sourced to the predominance of the biomedical approach to most aspects of service delivery.

This research is underpinned by feminist standpoint epistemology in its rejection of traditional androcentric foundations of epistemology in science (Mendel 2007) and 'the view from nowhere' (Diaz 2002, p. 249) or as Haraway puts it, 'the god trick' (Haraway 1991, cited in Mendel 2007). It asserts that women's lived experiences are a crucial aspect of knowledge. Feminist standpoint epistemology asserts that 'all knowledge is constructed in a specific matrix of physical location, history, culture and interests' (Harding 1998, in Sprague 2005, p.41).

It should be noted that this research is not seeking to discover a universal category of or *the* voice of women; rather it uncovers a range of voices from a range of experiences and is based on the fluid boundaries of a more permeable epistemology; an aim advocated by Shildrick (1997). This situated knowledge of multiple and intersecting forms of oppression places emphasis on cultural, historical and local context and 'positionings in the world' (Mendel 2007, p.8).

In addition to the phenomenological approach of the research, there is a social justice aim, namely that the research findings might be used to influence service delivery and models of practice. This then could constitute a form of feminist action research because it specifically seeks women's experiences as a basis for advocacy for change to current understanding and practices, at individual level and collective levels (Reid 2004). It is anticipated that journal articles and conference presentations might generate debate and 'conversations' about the research outcomes adding to impetus for change to service delivery and policy in the assisted reproduction field (Wendt and Boylan 2008).

The research also adheres to the principles of anti-oppressive social work research (Strier 2006) in its aim to decrease oppression of AR clients and to hear silenced voices. This project's grounded, phenomenological base complements the anti-oppressive model as does the researcher's commitment to establishing a safe, active environment for research participation. The aim of creating 'knowledge that empowers the disadvantaged' can help people's struggle for self-determination and the act of

participating in a research project of this nature could be 'psychologically empowering to those not used to people being interested in their opinions' (Sprague 2005, p.163).

Given the ontological and epistemological perspectives of this research, it follows that the methodology should produce rich qualitative information directly from women who have experienced AR and who currently live in non-metropolitan locations. Some options for gathering such information include focus groups or group interviews, or via a series of interviews using an interview team and/or research interviews with individual participants. This research used semi-structured in-depth research interviews, all of which were conducted by the researcher. The other options were not practicable given the time frames involved, ethical considerations (especially anonymity of participants in group situations), resource limitations (e.g. travel and venue limitations for groups) and also the fact that this is a doctoral research project for which the researcher is solely responsible.

This method employed a reflexive heuristic and approached each of the in-depth interviews as an *exchange* between researcher and participant for the purpose of gaining rich descriptions of human experience, directly from people who have this experience (Groenewald 2004). This is an effective way to show meanings in context and emphasises that research is a *process* and an *interaction* between equal subjects (Diaz 2002).

Ethical considerations

This study was approved by Charles Sturt University's Ethics in Human Research Committee. The ethical considerations centred on ensuring that participants were adequately informed of the purpose and aims of the research, the time-frames involved, confidentiality issues and potential risks, in order to make an informed decision about their participation. The purpose of the research was communicated in a variety of ways, ranging from the initial notices and advertisements aimed at recruiting participants, to the initial telephone and email contact with each woman, follow-up discussions with some women were held, and a formal information sheet about the research project was distributed and discussed at the time of interview.

To establish and maintain confidentiality, each woman was advised that her name and other potentially identifying details would not be used in material produced from the research. After interviews were completed, the researcher gave each participant and her partner a pseudonym which appear in research reports and other written material, in presentations, as well as the transcripts, data storage and coding files and the audio files and back-ups of each interview. In addition to confidentiality, the pseudonyms also serve to maintain the personhood of individual participants. All excerpts used in the following chapters are attributed to their source and the pseudonym used to identify each woman as a unique participant in the project.

At the time of interview and before each interview actually commenced, each woman was given another copy of the information sheet and a consent form to read and sign. Each woman also received the researcher's business card and another card with contact numbers for local support services, should they require psychosocial support after the research interview. Along with requirements about confidentiality, the 'support services card' distributed was a stipulation of the University's ethics committee aimed at minimising any potential negative impacts of the research process. Given the sensitive nature of the research topic it was foreseeable that for some participants the research process could potentially raise unresolved issues and cause distress. This aspect of the research was discussed with each woman prior to the consent form being signed in order to ensure that the interview was voluntary and based on informed consent regarding such unintended, possible outcomes. It was stressed to each woman that she was in control of what she did or did not disclose during the interview, that the level of detail disclosed was also hers to decide and that the interview could be discontinued temporarily or permanently at her request at any stage. *Appendix One* contains copies of the advertisements, notices, information sheet, consent form and the information card used in this study.

Locating the research participants

Qualitative research of this nature relies on the voluntary participation of people who have experienced the issue under investigation. A variety of recruitment methods were used to reach as wide a range of people as possible and to make it attractive for

them to participate. To this end, considerable thought was given as to the most likely means of attracting women who had used, or who were currently using AR services. Methods used to advertise the research were: noticeboard displays about the research at various locations, including AR clinics, women's health centres, community health centres, community noticeboards and at medical practitioners' offices; liaison with women's health nurses in several area health services to distribute information about the research into small community centres and outreach services; advertisements in several local newspapers; online advertisement with specialist AR organisations.

It is acknowledged that the recruitment methods used may well have produced some bias in 'the sample' of participants because most recruitment methods depend on potential participants being current health service users, being literate, having access to the internet, on being willing to volunteer and on having the time to spare to engage in an interview.

In keeping with the central aims of this project, the following criteria were used for the selection of research participants. Participants needed to be:

- female;
- past or present use of assisted reproduction services in Australia; and,
- currently living in an Australian non-metropolitan location.

The first attempt to recruit participants was direct liaison with several AR clinics based in regional centres - one primary clinic and one network of primary/satellite clinics with clinics in many regional locations. Initial contact was via telephone with clinic coordinators and follow-up information about the research was emailed to service providers who expressed some interest helping to recruit participants. The service providers were asked only to display a notice about the research in their waiting area. There was no request for active recruitment of participants or active information-giving or promotion of the research and there was no request for any patient information to be given to the researcher about service users. A follow-up meeting in-person was also conducted with one clinic coordinator, who was very interested and helpful but not confident that the clinic's directors would want to be associated with the research. All clinic coordinators contacted undertook to discuss the research at

their next meeting with clinic directors. All clinics eventually declined to display the notice and only one clinic expressed significant interest in being informed of the research outcomes.

Liaison with Area Health Services via community health centres and women's health nurses in particular was much more successful. All women's health nurses were contacted by telephone and follow-up email and all were enthusiastic and supportive of the project's aims. These nurses distributed the research notice to various small community health and outreach centres in their area.

Notices were also displayed at several other locations – on community noticeboards in town libraries and one in a shopping centre at a large regional centre. Advertisements were placed in several regional newspapers and one notice placed on an online AR support group's site.

Thirty women who had used or were currently using assisted reproduction services responded and the most effective method of attracting research participants proved to be the newspaper advertisements with twenty-two women in total having been recruited in this manner. Eight women responded to notices they had seen displayed at various locations, including at community health centres (n=4), community libraries (n=1), women's health centres (n=2), and a shopping centre (n=1). Twenty three participants (82%) were located in large regional centres, three (11%) were in small rural centres and four (14%) were located in very small rural centres.

The women used a variety of methods to make initial contact with the researcher: eighteen telephoned and spoke directly with the researcher; ten emailed and, one used a mobile telephone text message. The researcher then made follow-up telephone calls to each woman to discuss the nature of the research in more detail. Once it was established that they wished to proceed, the information sheet was either emailed or posted to them. Only one woman was completely ineligible to participate due to her geographic location (outer metropolitan) and one woman had not used AR in Australia; she agreed to participate in a pilot interview and this helped to refine the audio recording process and the interview schedule. Thus, twenty-eight women were available to be interviewed for the study.

After the women had received the information sheet, they made further contact with the researcher and a mutually convenient time for an interview was organised.

The interview process, data production & storage

In the opening phase of each interview, once written consent had been given, a great deal of care was taken by the researcher to clarify the distinction between a therapeutic interview and a research interview. The researcher identified herself as a doctoral student who also teaches social work at university and stressed from the outset that if supportive counselling was required that this could be arranged but that it was not the purpose of the interview. The 'support services' card was also a useful, concrete way of reinforcing this distinction. Each woman was also asked what had motivated her to participate in the research and what she hoped for in terms of outcomes. This also gave an indication of the participant's perspective of the process and led to rich information being gathered on the complexities of relationships in qualitative research.

In poststructuralist qualitative research, these complexities must be recognised and there needs to be a measure of comfort with such complexities and multiple definitions of the interview experience and the relationship between researcher and participant (Pini 2004). While this approach does not strictly represent 'equality' between researcher and participant in the process, at least these roles were directly discussed and respectfully defined from the outset, rather than there being a pretence of pure equality that would have been unattainable in this relational context. This honest approach to the interview process also reflects Heidegger's ontological principles of authentic existence and reciprocity in interactions and is a departure from Husserl's idea of 'bracketing' (Morse 1994).

Wendt and Boylan (2008, p.604-606) also advocate for this sort of 'co-construction' of the interview process and propose that the almost inevitable inequalities in the research relationship can be minimised via acknowledgement and attempting wherever possible to acknowledge the participants' multiple identities, other roles and the 'many storylines that intersect with one another'. Thorne, Reimer Kirkham & O'Flynn-Magee (2004, p.12) also acknowledge that no matter how collaborative and

participatory the research process is that the researcher is the one who 'ultimately determines what constitutes data, which data arise to relevance' and 'how the final conceptualisations portraying those data will be structured'.

While the importance of approaching the interview as a research interview is clear, it should also be noted that there are similarities between research and therapeutic interviews. An effective interviewer in either context needs to establish rapport with the person being interviewed, they need to pay attention to what is being said so that purposeful questions, prompts and communication microskills can be used and ethical issues addressed. Both types of interview require a conscious methodic form of questioning, consciousness of interaction and a critical consciousness of the content of what is being said and one's own concurrent interpretation of what is being said (Morse 1994, p.307).

The first interview was conducted in June 2004 and the final interview was completed in May 2005. Twenty seven of the twenty eight women interviewed chose to be interviewed in their own homes and one chose to be interviewed at her place of employment. Using the AIHW (2004b) geographical classification system for regional, rural and remote health areas, all research participants were living in 'outer regional areas'. Twenty-five of the women were living in New South Wales at the time of interview and three were in Victoria. A more detailed description of the participants' contexts is provided in the next chapter.

Most interviews were approximately 90 minutes in duration with a range of 65 minutes to 130 minutes. A semi-structured interview schedule was used with a demographic data collection sheet to capture basic information about age, marital status, income, occupation, offspring, and location (*Appendix Two*). The interview schedule was designed to encourage participants to be as self-directed as possible in the information they disclosed to the researcher.

There were no set questions recorded on the semi-structured interview schedule. The schedule was more a list of key words used to prompt the interviewer to consistently cover certain issues. These prompts were based on presuppositions of what would be relevant to participants. These conceptual, theoretical lines of enquiry were derived

from the literature review as well as from discussion with the research supervisors. There was a conscious effort to ask many open questions during the interview so as to encourage the participant to tell her own story and to ensure 'room for the unexpected to emerge' (Conroy 2005, p.36), rather than to narrowly direct the path of each interview. So each interview had a broadly consistent overall structure while still allowing for individual variation during each interview. This approach to the interviews complements the interpretive phenomenological approach and again the researcher spoke directly to each woman about the purpose of the interview schedule usually along the lines of 'there are no set questions, just these key words to keep me on track'. This explicit negotiation of the parameters of the relationship also reflects the interpretive, post-structural approach to knowledge generation.

The interview schedule was also developed with reference to minimising the likelihood of participant distress. The most sensitive topics and prompts were generally raised in the middle phase of the interview, after sufficient rapport has been built between the researcher and participant. The ending phase of the interview was generally used to summarise and to conclude the interview in the most positive manner possible. Each woman was asked whether she had any recommendations for other women contemplating AR and for recommendations and feedback on service delivery for the clinic(s) used. This strategy recognises the participants' power in clarifying and interpreting the information gained given during the interviews and also in negotiating the outcomes of the research and the contributing to the conversations the research outcomes might eventually stimulate (Wendt & Boylan 2008). This method then is consistent with the epistemology of the project and recognises the 'social and political context...and consequences for people's lives' and allows space 'for critical reflection and creativity' (Sprague 2005, p.5).

Interviews were recorded using a digital voice recorder. After each interview, the digital audio recording was copied to a secure file on the researcher's desktop computer. This audio file was then converted to a format where a hard copy of the interview could be saved to compact disc (CD). The CD copies were then securely stored and only accessible to the researcher and two research assistants who helped

to transcribe the audio recordings to text-based Microsoft Word documents. In addition to allocating pseudonyms to participants after each interview, other identifying details were systematically changed during transcription and proof-reading of transcripts and also during the coding process. In accordance with the University's ethical requirements, all research notes, CDs, transcripts, etc will remain in secure storage for at least five years after the completion of the project; after this time, they will be destroyed.

The interpretive process

As much as possible, the terminology and practices of positivism are avoided in order to maintain a coherent interpretive, poststructural approach reflected in language as much as it is in various other ways - ontologically, epistemologically and methodologically. So the terms 'data' and 'data analysis' will be replaced by terminology more in keeping with the conceptual orientation of the study. The pervasiveness of positivism in the language surrounding research and academic endeavour is sometimes hard to resist when computer software has been used as a tool to 'code the data'/interpret the interviews. Even the word 'interpret' carries the baggage of positivism and casts the researcher as a somewhat distant analyst who is taking the raw materials from interviewees and making expert sense of it, that is using 'abstract individuation' and thereby objectifying participants in the process (Sprague 2005, p.18).

To avoid such unilateral interpretation and abstraction and to avoid departure from the interpretive mode and in the interests of preserving as much reciprocity as possible in the process, all participants were given the opportunity to contact the researcher after their interview should they wish to add or clarify information. A summary of the major themes from all of the interviews was also sent to each participant and they were invited to make further comment on this collation of interview themes (see *Appendix Two*). At the time of the interview, many women indicated that they were very interested in what other women would have to say about AR. This and other participation issues will be discussed in more detail in the

following chapter. (Only two participants made further contact with the researcher, both to offer additional information and resources from media reports).

As each interview was transcribed into a text document, it was imported into the *NVivo 7* qualitative data handling software program. *NVivo 7* was used essentially as a sophisticated way of organising the themes initially identified manually from hard copies of the transcripts and then 'cutting and pasting' themes from the transcripts into 'codes' within the database. So each interview was replayed, then transcribed, then the transcript read, descriptive information was collated and topics were tentatively coded. Once all transcripts had been coded in this way, broader patterns in the topic codes could be grouped together into larger analytic codes that reflected the major theme of that code. This process ensured that the codes emerged from the interviews and that interviews were not 'slotted' into pre-existing codes (Denzin and Lincoln 2000).

This process meant that the initial tentative topic codes were numerous (eighty separate codes – see *Appendix Three*). To make the themes more accessible for interpretation, patterns in the topic codes were then organised into thirty thematic, analytic codes:

Table 2 Thematic codes

Access	Advice to clinic	Advice to others
Alternative therapies	AR experiences (procedures)	Clinic – nature, description of
Control – agency	Decision-making –duration,	Embryos
Expectations – initial understanding, likelihood of success	Impacts – physical, financial, emotional, relationships, social, employment	'infertility' – reasons
Information	Injections	Involuntary childlessness
Man – men's needs	Media	Motherhood
Motivations to participate	Natural success	Opinion
Others' reactions	Outcomes	Postnatal
Pregnancy	Privacy	Rural Health
Spirituality	Support	Woman

Care needed to be taken in this process not to fragment interviews into fine, tight codes and to thereby risk losing the richness and complexity of the information. There can be a temptation to prise apart each sentence, sometimes each phrase or word, from the interview transcripts and to allocate the various bits to separate codes, but to do this would be the lose important contextual detail and possibly to alter the meaning of the information itself. As a way of guarding against this, a précis of each whole interview was also written and parts of this appear in the next chapter. Also, such fine coding was resisted and for the most part only larger excerpts from interviews were organised into the relevant code. A feature of the software itself offers another check against fragmentation in that the researcher is able to collate reports on the proportion of time each participant spent talking about a particular theme or themes. This helps the researcher maintain a sense of perspective on each interview and on the significance of each theme for individual participants. Care was also taken to preserve the exceptional, unusual responses and to thereby identify the uniqueness in participants' information as well as the context, patterns and themes (Groenewald 2004).

 NVivo 7 computer software was used in a very basic way in this study and its more sophisticated functions were not utilised and not pertinent to the interpretive endeavour at hand. *NVivo 7* was a useful tool and aided in the process of sorting the information into manageable portions to interpret the emergent themes from the interviews. It needs to be noted that the software is a *tool* and not a method in itself and that it cannot perform interpretive or analytical functions for the user. Auto-coding, complex searches, modelling and frequencies for example were not used at any stage to 'process' the interview transcripts.

In terms of the hermeneutic spiral, the interpretation of interviews was indeed a fluid process commencing concurrently as the interviews were in progress, as well as via the researcher's notes during the interviewing phase of the project, and from discussion with research supervisors and colleagues, during the transcription and replay processes, as well as with reference to the literature review and feedback from participants.

Once the analytic themes from the interviews were collated into separate 'reports', they were printed as hard copy documents and re-read and 'post-coded' (Richards 2005, p.98). This process helped to conceptualise the participants' information (Glaser 2002) which is described and discussed in the following chapters. In these chapters, the participants' information will be shown to have considerable conceptual power and this experiential knowledge will contribute to forming a more holistic and fluid knowledge base in the field of assisted reproduction.

Research reliability

The credibility of the interpretations arising from this research will depend in large part on how consistently and logically the narratives are presented and upon how effectively the complexities in participants' stories are described and analysed. The reliability of the research also depends on the logical consistency between the conceptual framework, the literature review and the method used to gather information from participants. The limitations of the research are mostly in terms of its generalisability in the positivist sense, but given that this is not a positivist project, that criticism holds little power.

Consistency and credibility also relate to the researcher's ability to maintain a standpoint that focuses on the participants' views and to 'work from the standpoint of the disadvantaged' (Sprague 2005, p.162). This standpoint seeks to learn more about the individual practices and experiences of participants and this is the principle that underpins the use of the semi-structured approach to the interviews and the communication skills used during interviews. Another element of the research process is to ensure that interpretations are grounded in the interests and experiences of participants and involve recognising patterns in interview transcripts that indicate 'the workings of social power and powerlessness' (Sprague 2005, p.162). The following chapters are testament to this process in that a range of excerpts from interviews are incorporated into a discussion of the themes of the project as they have emerged from the 'data'.

The writing-up process

To maintain the richness of the participants' information, the writing-up of the research must preserve the quality, complexity and context of the information. Considerable care was taken to preserve the participants' individuality and to ensure that exceptional responses as well as common patterns emerged in the process. The consistent use of participants' pseudonyms avoids objectifying the participants and helps to retain the individuality and personhood of each participant and it maintains the link between the information and its source rather than fracturing this connection.

From the thirty analytic codes (Table 2) and subsequent post-coding, a logical way of organising a large amount of complex information needed to be developed so that there was some sense of an overall narrative or form to the presentation of the information. It is important to be able to effectively communicate research findings as this is a crucial part in contributing to the knowledge base. The skill of engaging the research audience could well be the first step in advocating for social and political change and in making a substantial contribution to the knowledge base.

Several options were considered to organise the material to meet these needs; the first was to consider micro-level themes relating to women at the individual level, her partner and her family and friends, then to focus on meso-level themes such as the clinic, clinic staff and then to consider macro-level issues like spirituality, rural health, etc. Another option was to organise the material along more chronological lines and in terms of the journey or 'story' of the experiences of assisted conception. This interpretive order was more appealing as it captured the stories in a more naturalistic and lively way and in fact reflects how the participants often presented their information at interview in response to the initial prompt to describe their involvement with AR.

Thus the participants' information is presented by first contextualising the participants, then presenting the information on their experiences of involuntary childlessness and the decision to try assisted conception – the pre-AR phase. The following two chapters focus on the active AR phase – the clinics used and what they were like, interactions with clinic staff and experiences of actual procedures and issues relating to quality of

care. The participants' psychosocial support needs are written-up in Chapter Eleven due to the amount of information provided on this issue and as a reflection of the overall focus of this study. Chapter Twelve is focused on the outcomes of AR and on reflecting on the experience in general – the post AR phase.

In the following chapters wherever possible direct quotations from research participants have been used to ensure that the account is multi-vocal (Sprague 2005) and wherever possible the participants' words have been used verbatim. Breaks in quotations (indicated by a series of full stops ....) to maintain the flow of information and to exclude some of the artefacts of dialogue such as 'um', 'ah', 'you know', and other paralinguistic cues. Often however, the individual qualities of each woman's responses have been maintained and not sanitised to a point where individuality, humour and tone are diminished. Using quotations in this way ensures that research participants remain as participatory, active voices in the process and not to be abstracted out of the process (Sprague 2005).

In summary, this chapter has outlined how the interpretive research process (methodology) is consistent with the feminist poststructuralist epistemology of the project and its ontological base in phenomenology. As Sprague (2005, p.5) argues, 'methodology emerges as the terrain where philosophy and action meet, where the implications for what we believe for how we should proceed get worked out'.

So we are now at the point where the research as planned from the proposal stage through the ethics approval process and the recruitment phase has attracted a number of women who are willing to speak to the researcher about their lived experience of AR. These women have spoken to the researcher and the researcher has recorded, transcribed and organised the information. Who then are these women and why would someone volunteer to give up some of their time to revisit their experiences of AR? The following chapter provides an overview of the women who so generously contributed their time and their perspectives to the research. While maintaining the anonymity of the participants, it is useful to explore their characteristics, their motivations and their broad context before the information from the interviews is

discussed in finer detail in later chapters. The following chapters restore 'epistemic

privilege' (Sprague 2005) to the women who have experienced assisted reproduction.

Chapter 7 - Overview of participants

As this is a poststructuralist, interpretive project, before presenting detailed accounts of what motivated these women to participate in the research project and what they said, it is necessary to convey some sense of the broad contexts of participants; their demographic details, location, general socioeconomic and family contexts while maintaining their anonymity. It is important to note however that the information is not intended to establish whether or not the 'sample' is 'representative'. The epistemological base of this research is such that representative sampling is not strictly relevant. The intent is to undertake in-depth phenomenological analysis of volunteer participants' experiences of AR. Some themes will most likely be generalisable and testable in the positivist mode; some themes will be quite unique to this group or to individuals within this particular group. Consistent patterns and themes may also emerge from the transcripts of the interviews and these patterns, or 'hermeneutic shifts' are interpreted as part of a complex, fluid web of knowledge rather than as universal facts, as in the positivist mode (Conroy 2003).

The overview of participants is intended to place the social and physical contexts of these women at the forefront of the research information. It is intended to minimise the likelihood of separating the 'data' from its creators and to provide a richer appreciation for the women who chose to participate. To this end, it is important to personalise each participant with a pseudonym but to maintain participants' anonymity, pseudonyms have been de-coupled from other characteristics, see Table 3:

Table 3 Participants' pseudonyms

Pseudonym (partner pseudonym)			
Amber (Andy)	Ivy (Ian)	Kate (Kev)	Phoebe (Phil)
Anne (Alf)	Jacquie (Jim)	Kerrianne (Ken)	Sarah (Sam)
Belinda (Ben)	Jan (John)	Kylie (Karl)	Sharon (Steve)
Carmen (Cam)	Jane (Jake)	Leonie (Lewis)	Sue (Sean)
Clarissa (Colin)	Jenny (Jed)	Lily (Lyle)	Tina (Tim)
Elle (Evan)	Josie (Jock)	Lindi (Larry)	Toni (Trev)
Felicity (Fred)	Judith (Jeff)	Marion (Max)	Vikki (Vince)

Characteristics of research participants:

Age

At the time of interview, the youngest participant was aged 22 years and the oldest was aged 50 years. Most participants at the time of interview were in the 40-44 year age range. At the time of AR use, most were in the 35-39 years age group, see Table 4:

Table 4 Age range

Age range	At time of AR use	At time of interview
18-24	1 (3.6%)	1 (3.6%)
25-29	5 (17.9%)	2 (7.2%)
30-34	7 (25%)	4 (14.2%)
35-39	10 (35.7%)	6 (21.4%)
40-44	4 (14.2%)	11 (39.3%)
45+	1 (3.6%)	4 (14.2%)
Total	28 (100%)	28 (100%)

Location

Using the Rural, Remote and Metropolitan Areas (RRMA) system to classify location (AIHW 2004b) most participants (n = 21) at the time of interview, lived in large regional centres with populations of between 30,000 and 70,000 people. Five participants lived in very small rural centres with populations less than 5,000 and two participants were in regional centres with populations of between 5,000 and 9,000 people. All participants were based in non-coastal areas of inland, regional Australia so in this sense, the participants' locations are not typical of Australia's highly urbanised population which is concentrated (64%) along the east/south-east coast of the continent (ABS 2008).

Relationship status

In terms of relationship status the participants are quite homogenous with all currently in heterosexual couple relationships. Almost all participants (n=26) were in a formal marriage relationship, one had divorced and one was in a de-facto marriage relationship at the time of interview. There were no same-sex couples and at the time of AR use and no un-partnered women.

Ethnicity

The women who chose to participate in this study were predominantly Australian born (n=26); none of the women identified as Aboriginal Australian or Torres Strait Islander and only two were overseas born – both in English-speaking countries. ABS (2008) data shows that 24% of all Australians were born overseas, that 16% of all Australians speak a language other than English at home and that 2.5% of identify as Aboriginal or Torres Strait Islander.

Employment status

While most participants were in paid employment both at the time of AR use and at the time of interview, there was a marked reduction in the proportion of women in paid employment *after* AR, largely due to the fact that most participants had become mothers either as the result of AR or natural conception and had chosen to take time out from paid work to care for children, see Table 5:

Table 5 Employment status

Employment status	At time of AR use	At time of interview
Both in paid employment	27 (96.4%)	20 (71.4%)
Partner only in paid employment	1 (3.6%)	7 (25%)
Retired	0	1 (3.6%)

Occupation type

The occupations of participants and their partners were classified using the Australian Bureau of Statistics (2006) *Australia and New Zealand Classification of Occupations* (see Table 6). Participants' occupation type tended to be concentrated in the professional, management and clerical/administration categories and to be underrepresented in the trade, labourer and sales categories when compared with national data (ABS 2006).

Table 6 Occupation type

Occupation classification	% of participants (number)	National % (ABS 2008)
Trade	3.6% (1)	12.7
Labourer (including agricultural)	10.7% (3)	11.6
Clerical/administration	21.4% (6)	16.5
Sales	7.1% (2)	9.3
Community/personal service	7.1% (2)	3.8
Management	17.9%(5)	8.2
Professional	32.1% (9)	19.3

Household income

Most participants (82%) had household incomes in the average to high range with 18% of participants having lower than average household income when compared with ABS (2008) data (Table 6). Overall there was consistency of income levels from the time of service use to the time of interview with nineteen participants staying within the same income range. There was an upward trend in income for eight participants and only one participant's household income decreased overall, most likely due to retirement from the paid workforce. These trends in household income need to be considered in the context of the information relating to participants' occupation type (above) especially in relation to the concentration of occupations in the professional, management and clerical/administration categories.

Table 7 Household income range

Income range	At time of AR use	At time of interview
<$30,000	4 (14.3%)	3 (10.7%)
$30,000 – 50,000	4 (14.3%)	2 (7.1%)
$50,000 - 70,000	9 (32.1%)	9 (32.1%)
$70,000 – 100,000	4 (14.3%)	3 (10.7%)
$100,000+	7 (25%)	11 (39.3%)

Religious affiliation

An open question was used to determine whether or not participants had any religious affiliation. Most identified at least a loose affiliation to one of the mainstream Christian religions and 28.6% expressed no religious affiliation at all (see Table 7). This compares to ABS (2008) data on religious affiliation in Australia in the following ways: a comparatively higher proportion of participants identified as Anglican (35.7%) than the national data (19%); a slightly higher proportion identified as Catholic (28.6%) compared to national data (26%); a comparatively lower proportion of participants identified with other Christian religions (7.1%) compared to national data (19%) and; the proportion of participants who expressed no religious affiliation was fairly consistent with national data (28.6% participants/31% nationally). No participants identified a religious affiliation with a non-Christian religion compared to 6% of Australians nationally (ABS 2008).

Table 8 Religious affiliation

Religion	Number of participants self-identified	National % (ABS 2008)
Anglican	10 (35.7%)	19%
Catholic	8 (28.6%)	26%
Other Christian	2 (7.1%)	19%
No religious identification	8 (28.6%)	31%

Outcomes of AR

If AR's measure of success is a live-born child, four (14%) participants had no success with AR and twenty four (86%) had success (see Table 8). In comparison to Australia's national data on success after assisted conception whereby across all age groups, 17.3% give birth (Wang et al. 2008, pp.14-15) the participants are a relatively successful group.

A total of thirty four children had been born to the twenty four women who had conceived via AR, including four sets of twins and one set of triplets. Twelve women (43%) had also given birth to naturally-conceived live-born children, producing a total of twenty two naturally-conceived children, all singletons. Two women had not experienced a live birth via assisted or natural conception. The outcomes of AR for participants are atypical in terms of outcomes for all Australian service-users In relation to success. It is significant that few women who had no success with AR chose to participate in this research. Perhaps these women were unwilling to revisit their involuntary childlessness especially if there had been no resolution to their involuntary childlessness.

Table 9 Outcomes of AR

Women with children via assisted conception only	16 (57.1%)
Women with children via natural conception only	2 (7.1%)
Women with children via both assisted and natural conception	8 (28.6%)
Women with no children at time of interview	2 (7.1%)

Continuation of AR

Of the three women who were still using AR at the time of interview, all had one child via previous AR and no naturally conceived children. Five women who were unsure about the continuation of AR, four had experienced live birth via AR or natural conception and one woman had not experienced live birth. Twenty women had decided not to use further AR services and all but one of these women had experienced live birth either via previous AR or natural conception. Two women had used AR with no success, but had subsequently conceived naturally and sixteen women had given birth to children via assisted reproduction and had not given birth to any naturally conceived children.

Types of procedures used

The research participants had used a wide range of assisted reproduction procedures, everything from hormone therapy (ovarian stimulation), GIFT, IVF (fresh and frozen), ICSI, AI (partner), AI (donor), as well as IVF (using donor ova). The most commonly used procedure was IVF.

Overview of characteristics

Overall the demographic features of the participants are quite homogenous in many respects. Most live in large regional centres, most are in formal marriage relationships and most are aged in their 30s or mid-40s. There is very limited cultural diversity within the group with all but two of the participants being born in Australia and none identified as Aboriginal or Torres Strait Islander. Most participants' household incomes are in the above average to high range and there is an overrepresentation in professional, management and administration occupation types than the Australian average. Most participants had given birth to either naturally conceived or assisted conception children and only two remained involuntarily childless at the time of the interviews.

Now that the participants' broad demographic characteristics have been described and contextualised, the motivations for these women to participate in the research will be explored in detail in the following section.

What motivated these women to participate?

During the interviews, each woman was asked an open question about what had motivated her to participate in the research. Several significant themes emerged and for most women there seemed to be a mixture of reasons for volunteering to be interviewed. As discussed in the previous chapter, the relationship between the researcher and 'the researched' is a co-constructed one so it was appropriate to seek information from participants about their motivations to volunteer for the study. For all participants, the opportunity to be interviewed about their use of AR was seen, altruistically, as a way to potentially help others; eleven of the twenty eight

participants said that their contribution was a sort of *quid pro quo* in relation to what AR had offered them; four women stated that being interviewed was a way of helping to reconcile issues related to AR use and two women said that they regarded the interview as a ritual to end their AR experience. Eleven women spoke of the interview as a means to provide feedback about their experiences, positive and negative, when perhaps there had been little opportunity for formal feedback to the clinic(s) they had used. Eight women said they wanted to bring involuntary childlessness and AR out of the private realm and 'into the open'; three were curious about the latest social research and what other women had to say and three expressed curiosity about the researcher's motives. Five of the women had conducted research themselves and empathised with the challenges of recruiting participants and three women identified a need to highlight specific issues for rural and regional services users.

These responses demonstrate that for many women the act of participating in this research facilitated a hermeneutic shift in their frame of reference in that the decision to discuss their experiences of AR also served to validate those experiences and to reassert a degree of power and agency in relation to the experience. All of the women explicitly expressed positive feelings about their decision to participate and this is evidence of the empowering potential of the research act itself in that seeking opinions from people whose opinions about AR have not been actively sought in the past offers an opportunity to comment about a major life experience (Sprague 2005). The responses will now be discussed in more detail.

Helping others

The majority of participants identified the urge to help others as the overarching motivation to participate. Many spoke of wanting to ease the way for other women and hoped that their input might be an indirect way of connecting with others who have used, or who were currently using or contemplating the use of reproductive technology:

> *When I saw the ad I thought well, this is me and if I can help somebody else then why not? It's only taking a little bit of my time...I would like to help other women having to go through this because it is hard, no two ways about it. I thought well why not? If I can help, I can help. (Sue)*

> *If somebody gets something out of your experience ... to help somebody else down the line...Everybody's story is certainly unique. (Lindi)*

Lindi's comment emphasises the importance of phenomenological research and its experiential base. Lindi clearly states that her experiences could be relevant to others and she also asserts that each individual's experience is unique.

Two women also indicated that being part of the research was a way of highlighting the human aspects of biomedicine and asserting their own personhood:

When I saw the ad I said yes, yes! ... Look, people have their opinion about IVF whether it is based on religion or limited information; they don't know the human side of it ...Being more than a statistic...within the reproductive unit you are a statistic, you're not a face, not a name, a child, a success story or not-success story. So I want to be more than that...the real experience, not reduced to a number. (Marion)

Many of the women also commented on others' reactions to their participation. A few had been urged to participate by family and friends who had also seen either the advertisement or notice about the research. Some women experienced less-than-positive reactions from others; one woman's husband was perplexed as to why she would speak to a researcher at all - *'what would you want to do that for?' (Sharon).* Another woman's mother was concerned that confidential information had been leaked and that the researcher had somehow 'tracked down' her daughter. Most concerns seemed to stem from a fear that privacy would be breached and/or concerns about confidentiality. One could speculate that these types of fears are related to involuntary childlessness being such a private issue for most families and to the capacity for AR itself to threaten that privacy and thus participation in this research then being seen as another step towards making infertility even more public:

'I told Mum I was talking to you this morning about this and she said 'oh how did she find you? Is your information out there somewhere?' I said you'd advertised and I'd answered the ad and that was OK with her'. (Jacquie)

'Therapeutic' motivations

As discussed in the previous chapter, often the interview experience is defined in various ways by those present; the researcher's focus is mainly on the research question, the purpose of the study and their skills as an interviewer; the participant might well be defining the experience in a variety of complex ways which could well include their contribution to the knowledge base of an issue as well the interview being a sort of therapeutic tool for themselves. Four women directly acknowledged these therapeutic motivations and indicated that they appreciated the opportunity to at least ventilate their experiences to an interested person:

I guess I appreciate the opportunity to talk it through with somebody...It's good for us too it is something I am proud of and I like to talk about it and it is nice to be able to talk about it in a confidential situation and sort of be completely and utterly honest without having to hold back on certain things. I mean there are certain things about it that I don't want to discuss with other people because it is personal. It is nice to be able to voice them. (Lindi)

It should be noted that although these women identified a self-help aspect to the interview experience, that the researcher ensured that each participant understood the distinction between a therapeutic interview and a research interview. The

information card given to each participant with contact details for supportive follow-up counselling reinforced this message.

For some of the women who had positive experiences of AR, there was uncertainty about whether or not they would have participated in this research if their experiences had predominantly negative:

> *I suppose it was a fairly positive experience for me...If I'd had a horrible time of it and a really negative experience then I would be less likely to want to talk about it ...Because it is such a personal thing and if you don't have children at the end of it, who wants to re-live that? (Amber)*

> *I guess for me it was such a positive experience and for a lot of people it is not, so I thought that it was important that people know what it is like and important that you hear what the actual participants have to say. (Leonie)*

The participants who considered their experience to be negative overall were still motivated by altruism and a need to be heard:

> *...really horrible, I felt isolated and unsupported which is why I wanted to be part of this study. (Kerrianne)*

> *I did have a rough time with IVF and any of my ... concerns ... could help somebody else. (Kylie)*

Participation as *quid pro quo*

Almost all participants expressed gratitude that they had been able to access assisted conception services as an option to attempt to redress involuntary childlessness. Almost 40% of participants (11 women) also stated that their participation in this research was a way of making a contribution to knowledge about AR overall. Implicit in many responses of this nature was the view that assisted conception procedures had been pioneered by others via research and development and because it had useful to them that they owed something in return:

> *I always thought that I might donate eggs to help someone and ...you know I didn't do that so when I saw your ad my first thought was maybe I could do that, maybe that would provide some information that will help someone else at some point. (Jacquie)*

> *I just wanted to help. IVF helped us so I just wanted to turn around and help others if we can. (Lindi)*

Validation of the experience

Due to the considerable impacts of AR experiences on service-users' lives, it is understandable that once the experience comes to an end, one way or another, that some sort of ritual finalisation could be in order to effectively accept that part of one's life story. This seemed to be all the more important for those who had not had success

and for those who kept the whole AR experience very private. These themes will be discussed in more detail in following chapters, but at this point, the following excerpts exemplify these motivations to participate:

> *It was an important part of our life for quite a few years ... It will be a good thing almost for myself to go back and re-visit as well...I think in a way it will be sort of a closure as well. (Vikki)*

> *I thought well, yeah, I do want to be part of this because if I can't get success I do want to see better things come out of it for other women. That is the driving force. (Judith, tearfully)*

Opportunity to provide feedback on service delivery

Ten women had not been given the opportunity to provide feedback to their clinic and some had not taken up the opportunity to give feedback on service delivery issues and they saw their participation in this research as one way to redress this. Being able to communicate with a service about your experiences of service use is generally seen as indication of a balanced, mutual, respectful approach to service delivery; the absence of effectively timed and affirming service-user evaluations could be construed as disrespectful. For some women, there may have been an option to provide feedback at the time of service use, but in the context of their broader experiences of involuntary childlessness and of AR, they did not feel like it at the time. This information will also be discussed in greater detail in following chapters, but in terms of motivations to participate in this research, the following comments are indicative:

> *At the time you don't feel like going back to them and saying I wish you'd done that... So they really wouldn't have any way of knowing. (Clarissa)*

> *IVF needs to make some big improvements in how it practices. It is still, you know, it has come a long way but it's still got a way to go. (Judith)*

Bringing AR from the private into the public domain

Disrupting the 'private' nature of AR was another motivation identified by almost one-third (8) of all participants:

> *I am tired of this being such a taboo subject; people don't like to talk about it and I think if more people talk about it people feel more comfortable with it. (Clarissa)*

As the literature review revealed, AR has been another example in modern society where a gendered activity has often been separated from public discourse and into the private and often also silenced realm. It seems that speaking out about experiences consigned to the private realm is one way of reclaiming one's power and self-determination; the very act of shedding light on something to demystify it can help not only the one speaking out but also her audience.

Other motivations

The possibility of gaining information on other women's experiences was also mentioned by three participants:

> *It would be good to get a feel for what other people have thought. (Amber)*

> *A lot more people are not successful than they are successful – I want to know their story...You know the whole thing intrigues me. (Marion)*

Four participants were simply pleased that someone was interested in researching women's experiences of assisted conception:

> *It was just sort of interesting, I said oh someone is doing their PhD, what a good topic to do it on, I must ring and help. (Amber)*

> *The whole qualitative area of IVF is limited and hardly anything around at all... they have forgotten about people. (Kate)*

Three women were interested in my reasons for choosing AR as a topic:

> *Why are you doing this? ... What interest do you have that has brought this on? (Ivy)*

> *I was just interested in actually what you would want to know. (Amber, laughing)*

This mutuality in the research relationship is also a key feature of phenomenological, interpretive research in that the researcher's motivations or 'foregrounding' (Conroy 2003) need to be recognised and no pretence of strict neutrality attempted. Ivy was particularly keen to discover my driving force and it is an indicator of her assertiveness as well as the level of rapport in the interview situation that she was given the 'space' to ask. In fact a few other women asked directly and indirectly about my motivations and perhaps there was an assumption about shared experiences of involuntary childlessness and AR where in fact there was none. I usually responded to these sorts of questions in a generic way by affirming an interest in rural women's health issues in general and a commitment to seeking input from women who had used AR to add to our understanding of AR. The feminist approach to the project was not specified due to the risk of alienating participants who may not identify with feminism (Sachs 1996). In this sense then, it cannot be claimed that I was fully engaging in pure feminist research or in a truly equal exchange with participants in that some boundaries had been established around my own situation as a mother of four who has no experience of involuntary childlessness. This boundary was established partly to ensure that the focus was on the women telling their own stories rather than on the interviewer's circumstances and to indicate that the interview was for research rather than therapeutic, supportive or platonic purposes. So this is certainly imperfect in terms of the ideal of equality between researcher and participant but on balance, the ethical

imperatives of the research take precedence and the quality of disclosure was not apparently harmed by maintaining this degree of interviewer distance. In other ways the researcher was immediate and genuine with participants and rapport was effectively established with each woman as discussed in greater detail in the preceding chapter.

Rural issues:

> *In rural areas there is always a real lack of data on anything in terms of health. (Kate)*

> *Living in the country our experiences are different and I'd like to express my opinion. (Clarissa)*

Three participants said that they were keen to share their expertise as non-metropolitan women; they indicated their appreciation of their intersectional disadvantages as women using biomedical services and as women with experience of involuntary childlessness and as women living outside of metropolitan areas. In the following chapters more detail on many of these themes will emerge and rural health issues will be analysed, including health service delivery models - limitations and opportunities, confidentiality and privacy and access issues.

This chapter has provided a broad sketch of the women who participated and about some of the reasons why they chose to participate. The following chapters will consider the information they have provided and the major themes, theoretical and practical implications of their experiences will be explored. This exploration is for the most part organised in chronological order, starting with the experiences of involuntary childlessness, reasons for infertility (if any were diagnosed), through to expectations about motherhood and assisted reproduction.

Chapter 8 - Experiences of involuntary childlessness and choosing to try assisted reproduction

This chapter presents the participants' experiences of involuntary childlessness and the decision to try assisted reproduction; expectations about AR and prior knowledge of AR are also explored. Before the stories of the participants unfold in the next few chapters, it needs to be said that these are not the stories of broken women dragging themselves to medical clinics to be passively 'treated' for the disease of 'infertility'. These are not the stories of helpless, hapless women surrendering to (mostly) male doctors. These are not stories about women who unquestioningly and unconditionally seek idealised motherhood.

These are the stories of self-determining women trying to fulfil a desire for motherhood. These stories are from women who may be perfectly well and able but who for various other reasons remain involuntarily childless. These stories are told by women who have chosen to pursue the imperfect options offered by assisted reproduction; options all too often delivered in less-than-perfect ways. The decision to use AR is an attempt to deal with the dissonance that involuntary childlessness has brought into their lives; AR holds the promise of achieving consonance.

Involuntary childlessness

> *Nothing was happening and I was just concerned that something wasn't quite right. (Josie)*

Most women (approximately 80%) who participated in this research were not aware of any fertility issues before they started attempting pregnancy, although a few (approximately 20%) were aware that conception may be difficult to achieve due to previous gynaecological issues. Nearly one-third of the participants tried for natural conception for approximately two years before seeking further medical assessment. A little under one-third tried for 12 – 18 months and approximately 10% tried for between three and five years. Some of the participants did not definitively state how long they had tried for natural conception before seeking medical help.

All women initially consulted their general medical practitioner (GP) and participants who commented on this experience reported a range of initial recommendations varying from 'wait another year' (Lily) to being told that IVF was 'the only way to go' (Kerrianne). Some women were asked to keep basal body temperature charts to track their natural cycles and some, because of other symptoms, underwent exploratory surgery (laparoscopy) to determine the cause of infertility.

Seventy-one percent of participants were given a medical reason for their childlessness; 39% were told it was female factor infertility only, 14% were told that it was male factor infertility only and 18 % were told that a combination of male and

female factors contributed to the inability to conceive naturally. For 18%, no explanation was given for their infertility as there appeared to be no diagnosable issues with either the woman or the man. Eleven percent of participants did not definitively state the reasons for their involuntary childlessness. The rates of reported female-only, combined male-female and unexplained infertility are fairly consistent with ARTRC (2006) and RCRH (2007) data, but the rate of male-only infertility reported by participants in this research represents a smaller proportion of reasons for childlessness than the national data. The relatively large proportion of participants (3 of 28 women/11%) who did not definitively state the reasons for childlessness could account for some discrepancies in these figures.

Male factor fertility issues were generally reported as being related to low sperm count, low motility (movement) and/or the presence of anti-sperm antibodies. There was a broader range of female factor fertility issues reported by participants, including endometriosis, polycystic ovarian syndrome, anti- sperm antibodies, uterine abnormalities, ovarian tumour, fallopian tube damage from previous ectopic pregnancy, previous tubal ligation and reversal failure, as well as gynaecological damage from previous surgical procedures & subsequent infection. Two participants, Elle and Sarah, spoke of damage to their fallopian tubes in some detail. Both women reported having surgical procedures in their late adolescence and of experiencing subsequent infection (peritonitis) leading to tubal and other permanent, internal damage. Significantly, both women, who are located in different geographical areas, found that the doctors who initially performed the surgery were also the only doctors in their region from whom they could seek specialist assistance for infertility some years later. Both women spoke of the difficulty they then had in trusting their doctors again as both felt these doctors had been neglectful of their postoperative care at the time of the initial surgery:

> *It really annoyed me because if he had treated the problem at the time I wouldn't have to go through this* [IVF]'. *(Elle)*

The issue of access to medical practitioners and restricted choices in rural areas will be discussed in more detail in later chapters. That this paradox of having to trust a person to solve a problem when they are regarded as part of the cause of the problem in the first place was a significant source of dissonance for these women.

As identified in the literature review, despite the data on sources of infertility indicating that it is a shared issue across humankind, many women spoke of the 'courtesy stigma' they adopted (Roach-Anleu 1999, p.203) and of gender-biased assumptions - sometimes their own and often others'- that if there are fertility issues, then it must be the woman's 'fault':

> *It's funny when you tell people that you've had IVF or you know they find out or whatever, they automatically assume that the problem was with me. (Belinda)*

> *I seem to have blamed myself, the 1950s notion that the women always think it's their problem with fertility and it wasn't. (Judith)*

Like Judith, several other women also expressed feelings of guilt about not being able to have a child naturally. Some stated that they had contemplated leaving the relationship so that their partner would find someone else with whom to have children. Still others spoke of being thankful that they knew of their fertility challenges before entering into the relationship with their partner. They felt that this prior knowledge meant that he was then fully informed of the choice he was making in terms of possible long term childlessness. These women saw this as preferable to their partner finding out after partnering and the possibility that he would feel 'trapped' in a childless relationship:

> *Sometimes I felt like leaving because I used to think that he'll meet someone else and probably end up having children. (Lindi)*

> *I have been grateful that I knew it would be a problem so that when Fred and I were talking about getting married he knew there might be a problem because I think I would always have felt really guilty otherwise if we'd married and he'd found out later. I would have felt I had cheated him, whereas this way I always think that it was his decision to marry me and possibly never have kids. I know a lot of marriages have problems because they find out later they can't have kids, particularly if it's obvious that it's one party's problem. (Felicity)*

Some women spoke about how their male partners had reacted to infertility. One woman's first marriage had ended in violence and divorce which she attributed in large part to her infertility. Another woman spoke of how her husband 'deep down feels it's his fault...but it makes no difference to me at all' (Sue). Others also spoke of their partner's feelings and societal attitudes to male infertility and masculinity:

> *I think it is a manly thing as well, going and getting tested to make sure, you know, he is good enough. He didn't know he was never tested before. He couldn't stand having a low sperm count he would be devastated. (Elle)*

> *I think it might be harder for a man actually because they're brought up to be, you know, virile and all that...I think in our society men really like to think that they can produce the goods. (Jacquie)*

> *It hit him a lot harder than me, of course, being a man. But once he got over that it was like, OK let's get going. (Sue)*

Sue's comment reinforces research by Peterson et.al (2006) on gender differences in coping patterns in relation to infertility, with men being more likely to use a problem-solving approach to the issue. Elle and Jacquie's comments identify how traditional

constructions of masculinity rely on notions of virility and productivity and with women more likely to be seen as 'faulty' (Klein 1989b).

For the women who had been given a reason or reasons for infertility, there was comfort at least in having some information as to why natural conception was proving elusive. For those with 'unexplained' infertility, the cause of their situation remained 'a big mystery' (Lily) making it somewhat more difficult to initiate clear problem-solving strategies:

> *At least if you have a problem you can fix it or circumnavigate it but if there is no definite problem you just have to grin and bear it...There's no reason why we can't fall pregnant. (Carmen)*

> *We never actually could find a cause, we never had a diagnosis...and I think to even this day that has been the most frustrating thing. (Vikki)*

Some women even felt that despite there being given no diagnosable reason for infertility that it must still be their 'fault' and that it wasn't 'natural' for a woman not to be able to achieve pregnancy naturally:

> *I always felt it was my fault...even though it was unexplained, it was just like somebody grinding a knife into your back or into your heart and saying 'well it is your fault, what are you doing about it, why haven't you?' You know? Why haven't you? What's wrong with you? (Sharon)*

Impacts of involuntary childlessness

> *It was like the world falling down all around you. (Jenny)*

Almost without exception the participants spoke of their involuntary childlessness as one of the most significant life crises they had experienced, and this is certainly supported by previous research as discussed in the literature review (e.g. Blyth and Moore 2001). Most spoke of being 'devastated' or 'crying for days' and many of anger and frustration at not being able to conceive naturally. And almost without exception, women spoke of the decision to have children as a conscious choice, rather than a feeling of obligation or as an inevitable part of being a woman. The following comments underscore third wave feminist theories of individual agency in AR, exemplified by Throsby (2004), Gupta (2006) and Thompson (2005):

> *Having a child is not an easy choice, it not an obligation, it is not something you have to do, so be sure that you really want one and not feel that you have to because you are female. (Lindi)*

> *I was never getting married or having kids...Having kids wasn't desperately on my hit list of things I wanted in life, until I couldn't have them all of a sudden I did really want them. (Amber)*

118

Amber's comment also highlights an issue that affected several women – the feeling of disempowerment that came from involuntary childlessness. Many said that they felt a lack of control because of infertility and a need to 'fix' the issue as soon as possible:

> *Once the choice had been taken away from me that was hard to deal with because then I thought well there's really no choice any more. (Anne)*

> *At first I thought I shouldn't have to do this [IVF]; I should be able to conceive naturally. (Toni)*

Some spoke of their motivation to have children as a long standing life wish – of having 'always dreamt of having children' (Lily). Many had actively envisaged how many children they would produce and Sarah had decided that if she had not partnered by the age of thirty five, she would 'have a baby anyhow...I was always very determined to have babies...I was one of those women who would do anything to have a baby'.

However while some spoke of choice and self-determination, others identified strong, basic or visceral urges and of society's pronatalism as a powerful forces:

> *Society just expects you to have a child. (Sue)*

> *It's an incredible urge to have children, it's so much part of how we live, it's society. We're working with children, we're surrounded by children and we've come to a place where country towns still have high birth rates and ...I guess we just want to be part of the community and fit in. That drove us...It's just natural desire and a natural instinct to reproduce oneself. (Judith)*

> *You are a female, you should be able to produce a baby...To me it's just not natural and I found that really hard to deal with too. (Sharon)*

> *The whole world seems geared to women who fall pregnant easily and are happy mothers. (Sarah)*

This pronatalism also emerged as a major point of contention in first wave (and subsequent) feminist reaction to AR and it also clearly underpins the unhelpful and insensitive comments other people directed at these women and their partners about their childlessness. Almost without exception, each one of the participants had been asked directly about the absence of offspring and some women felt that people had assumed they were voluntarily childless. And while voluntary childlessness should be recognised as a legitimate choice in any case, many felt that the implication was that the women in particular were being selfish and choosing their career and /or material wealth over childbearing, indicating that childlessness whether by choice or not, is still not a readily accepted way of life, especially for women:

> *There was a bit of pressure, why hadn't we fallen pregnant? Was it a choice thing? You know people seemed to think we were being mean ...it was almost like a criticism. (Vikki)*

119

This woman said to a friend of mine – 'isn't it a shame Jacquie is so selfish, Jim would make such a lovely father and all she's doing is off having a career and I think that's very selfish. My friend said 'you've got no idea, they've been on IVF'...And she said it really upset her to think that people might be thinking we were really selfish when it wasn't the case at all. (Jacquie)

One person said to me that I was being selfish spending my money on a big house and that I would have been better off buying a smaller house and concentrate on a family. (Amber)

Some had tried to brush off these types of questions by using humour to defuse the lines of enquiry about childlessness:

When are you going to have a baby?' and I'd just say practise makes perfect. (Josie)

Often I would make a joke of it otherwise I probably would have cried. (Felicity)

Some had feigned indifference:

People used to ask and I'd just go - oh it will happen when it happens. (Josie)

I'd just say no, I wasn't interested in kids, and people thought that was true and they'd leave me alone. (Felicity)

Some had tried the direct approach:

My husband starting saying we are actually having trouble falling pregnant and it would really shut people up...you are quite raw...you know when every fibre of your being wants to be pregnant so yes, it was awful I would often say yes we would really like a baby and just always hope that was enough. (Sarah)

I actually said once – what if we can't have any? That usually stops them in their tracks. But then I feel guilty and awful...But people can be very nasty and cruel. (Amber)

Others had much more positive reactions from friends and family and some mentioned the unsolicited advice they had received from others:

A couple of girlfriends were really fantastic, really fantastic. You could ring them or you could have a cry or whatever and they were really good. (Jacquie)

The family was very loving and understanding but the anticipation was there as well ...they were wanting this child as much as we were. (Sue)

Then people knew we were trying to have a baby on IVF, you know lots of advice 'tell her mother to give her parsley' or some old wive's tales...Everyone's an expert! (Jacquie)

Regardless of the responses to enquiries from others, most women found these types of questions 'hurtful' and said that they added to the stress of involuntary

childlessness. Many said they were offended that others, even if they were only minor acquaintances, felt that they had permission to ask such questions. As Anne said:

> *It annoys me when people keep hounding people about why they haven't got children; obviously it's either a choice or it's not. (Anne)*

Perhaps the issue that seemed to irritate many of the participants was that of being labelled 'infertile'. Many women spoke of not wanting to be identified in such a way, of not wanting to be 'one of those *poor women* who can't have children' (Sarah). Sarah's comments indicate her agency and her resistance to the notion that womanhood, or femininity hinges on motherhood and that childless women are somehow 'faulty' or 'deviant' or pitiable.

Many participants also acknowledged that some people would like to be helpful or to be sympathetic and but that they lacked knowledge of how to respond in a constructive manner. There were quite a few comments about how some people seemed to minimise the impacts of involuntary childlessness and tried to be helpful by suggesting substitutes like overseas holidays and material possessions to compensate for childlessness. In addition to this generalised uncertainty in responses, Felicity spoke of her experience of male doctors' attitudes:

> *I guess I have only seen male doctors since I have been trying to get pregnant but I think that they think that you just have lots of sex and it is fun when you are desperately trying to have a baby...I think the specialists understand but not the GPs...I don't really think they treat it as a serious problem. (Felicity)*

Responses to involuntary childlessness

> *Everyone I knew was falling pregnant and having babies and it was like every single person was pregnant...has a pram...There were babies everywhere. (Anne)*

Several women spoke of trying to use avoidance strategies to cope with situations where women with babies might be. Shopping centres were identified as decidedly difficult places and celebrations like Mother's Day also featured in participants' comments. Some had experienced being in waiting rooms at AR clinics with women and their children and most found this particularly challenging. Many had also experienced the oversensitivity and awkwardness of family and friends, particularly at times when a new pregnancy needed to be announced. The following comment from Jane demonstrates the impossibility of these avoidance strategies as well as the impacts of being constantly reminded of what you do not have:

> *Jake's Mum said to me once 'just look out the window and think of something else'. I said well when I go down the street make sure no mother and her baby are walking down the street, make sure that when I go to the doctors that there are no crying babies, make sure when I go shopping in shopping centres – because they are horrible*

places when you are trying to get pregnant, built for mothers and babies and prams. I never felt claustrophobic in my life like I did then and I just had to get out of there. I couldn't look at another mother and her baby walking around; it is really in your face all the time. (Jane)

One participant spoke of how she kept her secondary infertility and use of AR very private with only her partner and one other person knowing. She spoke of her withdrawal from her usual activities and avoidance of friends and social situations and the ongoing, long-term effects this coping strategy was still having:

I found I withdrew. You don't emotionally attach yourself to people or their children to a certain extent, it can't touch you...I think I did emotionally withdraw and now I can't get back (tearful)... You emotionally withdraw to the point where you can't get back again. (Vikki, crying)

Most participants spoke in some detail of their grief in relation to involuntary childlessness. Many identified feeling initial shock and disbelief ('I shouldn't have to do this I should be able to conceive naturally – why can't I have a kid?' - Toni), through to tearfulness ('I cried for days' - Jan), anger and depression. Some described how they had moved on to try to integrate the experience and take action to attempt to remediate the situation:

I just kept saying - I can't have children, I can't have children and Mum said you can have children you just have to go through a different way, she was really supportive...she helped me deal with that. (Elle)

To compound feelings of loss, many described moving through phases of grief and loss as like moving in a seemingly endless loop of hope, despair, repair and back to hope again with each menstrual cycle – the 'complicated grief and loss' of involuntary childlessness (Lechner et. al 2007, p.288) . Several women described this cyclical pattern of grief and loss and how each month could be a disappointment and how involuntary childlessness as a constant, something that 'you can't get away from' (Jane).

For some women, feelings of anger and injustice were at times directed at other people with children especially those who were perceived as ungrateful or unkind to their children ('How come she gets a baby and I don't?' – Jacquie). Many described feeling angry and upset if they witnessed negative behaviour towards children such as swearing, physical punishment or perceived neglect. In most rural and regional communities in Australia the rate of adolescent parenthood is relatively high (Quine et al. 2003) thus further reducing the range of 'pain free zones' for women in particular in rural areas (Schmidt et.al 2005, 1050). Many commented on seeing very young mothers and babies and feeling resentful towards them for the ease with which these young women had produced babies. Most also recognised the source of their feelings

as resentment about their own situations as opposed to merely being judgemental about others:

> *I used to walk down the street and I would see these little seventeen year olds with a baby ... and you would reckon there was a million of them all lined up just to torment you. I used to get really resentful. I used to think it's not fair and then I would think well yes, it is, that's life. (Lindi)*

> *Why us when there's so many kids out there that are born to parents that really don't want them? That was hard to deal with...Why us? Why did it happen to us?...That was just kind of a selfish moment trying to justify what's happened, but then it was well, this is how it's going to be so just kind of deal with it. (Belinda)*

For most who participated in this research the acceptance or resolution of their situation came via the eventual birth of children either via AR or natural conception (over 90%). Some said that in hindsight, they 'had the best of both worlds' (Jacquie) and that their experience of involuntary childlessness had brought positives such as a heightened appreciation of the children they eventually had and/or opportunities to travel and/or acquire material possessions and/or to advance careers and acquire additional qualifications:

> *The little presents, like large presents actually, as consolation prizes, as a way of coping. It is not how my husband and I coped but friends went out and bought a boat and a big four-wheel-drive and a few other little trinkets but she said you know she would give it all up tomorrow to have a child. (Amber)*

> *We travelled a lot to take our minds off it...And as much as we enjoyed all that, it's a poor substitute. (Carmen)*

For those who did not experience successful pregnancies, acceptance was described as a much more difficult task and the use of AR was at the very least a way of coming to terms with the situation:

> *We're going to have to accept the future of a barren nest, so to speak...At least we gave it a go. They say you haven't got children; I can now turn around and say well I gave it a go, we just didn't have success...You just grab these opportunities and chances you have. (Judith)*

Judith's comment also highlights the importance of AR as an option for people who desire a child but face fertility challenges, albeit an imperfect option with no guarantees of it being fail-proof. Her comment indicates that not only did AR aid her problem-solving approach to involuntary childlessness but that it also gave her a level of protection against what she perceived as persistent negative community attitudes to childlessness. Many researchers have discussed the importance of active choice in AR, of AR providing some hope and a degree of empowerment, and of reproductive technology as the basis for a strategy of action, a rational choice for people faced with

involuntary childlessness (Gupta and Richters 2008; Porter and Bhattacharya 2008; Roach-Anleu 1999; Koch 1990). Other women spoke of using AR in this way:

Either we do this or we don't have children. (Belinda)

We previously decided that we would never do IVF, that it wasn't for us, but then when it came to the crunch ... once you get in the hot seat it is a completely different story. (Felicity)

Once the decision to try assisted conception had been made, what were the participants' expectations?

Initial expectations of assisted conception

I thought that was it, it was going to work the first time. (Tina)

Twenty five percent of participants said that they expected AR to be successful on the first cycle; most others had longer time frames in mind but still hoped they 'might just be lucky' (Judith). Only one woman said that she 'never really thought it would work' (Jacquie) and others identified success as being akin to 'the luck of the draw' (Carmen). Some described having a positive, relaxed approach and ongoing optimism – 'I had never allowed myself to believe that I couldn't conceive; I was going to conceive in some way' (Sarah).

I thought that it was going to work first go! Yeah, I remember sitting in the waiting room and there were these two ladies talking behind me saying 'oh this is my fourth attempt' and I'm thinking oh that's not going to happen to me, it's going to work first go and I was still there for the 10th, 11th, 12th go. And it wasn't until the 13th that I thought this is not going to work, yeah. So you do expect it to work every time and I think that's why it's such a crushing blow. (Carmen)

Quite a few women indicated very high levels of trust in biomedical science to solve their childlessness which again reflects the perception of AR as a mostly successful solution to involuntary childlessness as presented in the literature review (e.g. Winston 2007; Peddie et al. 2005). This tendency for service users to at least initially overestimate the likelihood of success is exemplified in the following comments:

I remember thinking I will just go and see him and he will do whatever he has to do and it would work and when it didn't that was, yeah, I was very disappointed because I didn't even consider that it wouldn't work. (Anne)

I suppose I thought it would just be successful because it was medical and it was just going to fix everything, but it doesn't. (Leonie)

These people are going to make me fall pregnant. (Lily)

Although as a counterpoint to this trust in technology, Amber said that 'based on success rates we might as well be using a turkey baster'.

In terms of information about success rates given to service users by AR clinics, the participants had varying responses. Some were very positive about the range, clarity and accessibility of information provided to them and others felt that information was too complex, while others felt they had not been adequately informed on a range of matters, commonly to do with the likelihood of success. As discussed in the literature review, where participants could recall an actual success rate they had been quoted, there was a tendency to overestimate the rate of success. The most common percentage success rates recalled were in the range of 20-25% per cycle. A small number of participants said that success rates were in the 50-70% range. The actual overall success rate in Australia is that 17.3% of service users per treatment cycle started for all age groups will have a live born child as a result of their AR use (ARTRC 2006).

Most women had quite a thorough understanding of the complexities of estimating success in assisted conception; most spoke of the likelihood of success being dependent on a range of factors such as parental age, the nature of the fertility issue and the type of AR procedure. Several women said that their clinic had been 'straight up front' (Phoebe) about the likelihood of success although a few others felt that they were 'only told of all the success stories...it's always the positive stuff' (Kerrianne). Clarissa, for example was critical of what was defined as 'success' and her comments echo the recommendations of Wang et al. (2008) and the ARTRC review (2006) that outcomes measures should be communicated in accessible terms and that they should reflect the birth of live, healthy full term babies:

> *I went into it with my eyes open well and truly... Some of them fudge their results, don't they? There is success and there is success, like live births or pregnancies with a positive blood test are two very different things...that is not very fair to people. (Clarissa)*

Clarissa's comment emphasises that service users have a specific goal in mind when choosing to use AR: they want to redress their involuntary childlessness – to give birth to a child, to restore their life course (Thompson 2005). It is highly unlikely that anyone would attempt AR in order to achieve a positive blood test result (a clinical pregnancy) or to miscarry or to experience stillbirth, or premature birth with ongoing difficulties and that therefore measures of success using this as a definition for success are not meaningful measures at all.

Prior knowledge of assisted reproduction

> *I needed as much information as I could get to give me some sort of control. (Anne)*

Approximately one-quarter of participants said they knew 'nothing' or 'not a lot' about assisted conception prior to service use. Some said they had a general knowledge from media coverage and the like but that they lacked detailed knowledge of what the procedures involved. For most participants, it was their clinic's nurse- coordinator who provided the bulk of information in addition to written material they had been given. Most had systematically been informed of AR basics as part of their orientation as new service-users. The clinics' waiting areas also proved useful sources for displaying further take-home written information for many women, especially in primary clinics (less so in satellite clinics where waiting areas were not AR client-specific). Some women said that this written information 'became like a bible' (Sue) to them and for most, even if the amount of written information seemed overwhelming initially, that at least they could pace themselves and refer back to the material as required. Many women specifically mentioned a brochure covering the 'emotional roller coaster' of IVF and many said that the rollercoaster image was a very apt way of describing the experience.

Other service users were also a source of information for quite a few participants. Many said that information directly from other women 'worked as a reality check' (Josie) and that 'you feel like you're not on your own' (Clarissa) after speaking with other women using AR. Most women had done their own information-gathering too including purchasing books on infertility and assisted conception, as well as online support groups (e.g. ACCESS) and online information. Some had the opportunity to attend information sessions provided by their clinic and a few clinics also produced their own regular newsletter. The information sessions seemed to be more a feature of metropolitan clinics rather than primary or satellite clinics in regional areas:

> *I noticed when I went to [the metropolitan] clinic there were information sessions about the whole thing... where you could go along with other prospective IVF people and learn all about it, whereas everything at the [regional satellite] clinic was done in one interview which in some ways is good but it doesn't allow you to meet anyone either. (Amber)*

The satellite clinics used by participants in this study did not seem to have adapted their service delivery model in terms of information and support for clients; they appeared to rely on one-off interviews/orientation sessions, on verbal information and on a limited range of written information. The lack of dedicated facilities at most satellite clinics and consequent lack of opportunity for ongoing display and availability of supplementary written information is an issue that requires attention and some adaptation of the service delivery model.

Service users however, were generally adept at seeking out information to suit their needs. The internet was a very popular method of obtaining information for most participants and many also indicated a critical approach to online information. Others

also used online resources such as chat rooms and blogs. The accessibility of information and the level of control, empowerment and independence this resource provided was important to many participants:

On the internet you get a much broader picture and ...we didn't get that information from our clinic...but I can get on the 'net and find out. (Amber)

I got on to a couple of internet forums and asked some questions and the range of responses was quite broad, from other women, which was good...I made sure I went on to a lot of clinics' websites...which were reasonably accurate and thorough...The local clinic's website is not wonderful...I wanted a full picture...and got a lot out of it. (Judith)

The need for ongoing availability and interpretation of information also emerged as important; many women stated that the initial quantity and complexity of information was 'overwhelming'. This indicates that a 'production line', one-off approach to information-giving might not be as effective as a more supportive, gradual or tailored approach to information-giving. For example, Felicity spoke of being aware of information on hyperstimulation given to her when she commenced AR, but when she was actually experiencing AR, she indicated that while she read the information initially that it really did not 'mean anything' to her at the time – 'it was the last thing on our minds at that time' (Felicity). Amber spoke of a need for information 'specific to me' and Judith also felt that information needed to be more tailored to individual service-users - 'one size doesn't fit all; individual women react differently to these things'. While it is obviously necessary to provide clear, accurate information about the technical aspects of procedures, many felt that the focus of the information was almost exclusively biomedical and that psycho-social aspects of the experience were sometimes neglected. Some felt that clinicians did not provide enough information immediately before a procedure and that there was an assumption that:

... if we'd reached that point of actually going through a procedure that [information-giving] had all been taken care of. (Vikki)

When we first went to see them [clinic] ...you kind of walked away and it was all a bit blurry...It was a lot of information to take in and it was all a bit overwhelming and a bit daunting to start off with. (Belinda)

The information was pretty clinical; it was factual, emotionless. (Ivy)

These comments clearly illustrate the limitations of a biomedical approach and its relegation of women to object status and the need for a bio-psycho-social approach to service delivery and to validate service users as active agents, as subjects, and to recognise the whole context of assisted reproduction. Clearly technical competence is vital but so too is adequate recognition and support for service users of reproductive technology.

Some participants felt that information provided by the clinic was biased and that more balanced information was needed, mainly in relation to success rates. This perceived bias was said to engender 'false hope' (Kerrianne) and to minimise the likely duration time of AR. The difficulty of on the one hand wanting a sure-fire remedy to childlessness while on the other hand acknowledging the reality of AR as offering only the *possibility* of success appeared to be a challenging juggling act for most participants:

> *The inaccuracy of it... the consistency of information and the need for them all to be telling you the one thing...The questions that I asked but when I asked the next person they would give me a different answer...It's all if, but when, maybe. There are no guarantees with any of it, which you're told. But you're also told of the success stories...it's always the positive stuff. (Kerrianne)*

One participant had missed out on her initial information session entirely due to what she perceived to be a very busy, 'rushed' treatment cycle at a satellite clinic and possibly the 'carelessness' of the coordinator. Some information had been given to her over the telephone and a brief explanation of how to self-inject was given when Elle went to the clinic to collect her medication. Despite not feeling well-informed about AR, Elle chose to participate in the clinic because she was not prepared to wait for another three months until the outreach clinic was available again. Elle's experience highlights another reason why satellite clinics need to adapt their information-giving strategies to reduce the likelihood of 'rushing' clients through the orientation phase.

The majority of participants said that in hindsight, more information, clarification, and/ or repetition of information was needed on a range of issues including:

- Psychosocial issues (10 women) – contact details for counselling support, groups, purpose of counselling, possible impacts of AR;
- Procedures (8 women) – purpose & detail of specific procedures, privacy, risks, costs, success rates;
- Long-term side effects (4 women) – for both women and offspring.
- Embryos (4 women) – storage options, costs, policies, transfer procedure (including number of embryos to be transferred);
- Ethical issues (1 woman) – religious and ethical considerations (e.g. ethics of in-vitro fertilisation).

These issues and other issues will be covered in more depth in the following chapters. Suffice it to say here, that access to reliable information was seen as crucial by participants especially given that most participants felt that they 'knew nothing much' about AR before deciding to use it. These women indicate that information needs to be appropriately paced, clearly presented, balanced, ongoing and accurate. The participants' comments reflect the NHMRC (2004) call for the provision of general

information to service users about clinical procedures to be more regulated and standardised, particularly in relation to the representation of success rates. They indicate that an *individual's* information needs and context are important in terms of information-giving and that the opportunity to revisit or seek clarification of information is necessary at all stages of service use. It is clear from what the participants have said that accessible, reliable information needs to be effectively disseminated so that informed consent to procedures and ongoing service-use can be given. In addition to being given reliable, standard information, it also emerges that individuals' information needs should be accommodated and information-giving should be tailored to each service user's needs.

This chapter described experiences of involuntary childlessness and the pathways to pursuing AR as a means to redress primary or secondary childlessness. The main focus now shifts from the preparatory phase and into a more detailed exploration of what women said about their time as active service users. The themes to be explored relate to the various impacts of medical procedures and regimes, emotionally, financially and physically, alternative and complementary measures undertaken, and privacy, control and support issues. This shift in focus is summarised by Amber in the following quote which illustrates that even with preparation and access to information, the actual experience of a phenomenon can still be somewhat of a shock:

> *Like I knew technically what was going to happen to me...the technicalities of it all ... I didn't give much thought to the actuality of it until it was happening and by then it was [pause] oh...(Amber)*

Chapter 9 - Active service use

The women who participated in this research have so far told of their experiences of involuntary childlessness and of their decision to try assisted conception. They have described some of their information needs prior to actual service use. This chapter presents information about the clinics used, procedures, access issues and how the participants, their partners and extended families experienced assisted conception. In particular, physical, financial, psychosocial and longer term impacts are presented and discussed.

Assisted Reproduction Clinics

Fifteen different clinics across five different States and Territories of Australia were used by participants. Two of these were regional satellite clinics, two were regional primary clinics, ten were metropolitan primary clinics and one was a metropolitan satellite clinic in an outer suburban location. Most participants used one clinic only (68%), 29% used two clinics and only one participant (3%) used three different clinics (see Table 9). Half of the participants had used AR within the last five years, 10.7% were actively using AR services at the time of interview and 17.8% were undecided about future use. All but one participant's service use was within fourteen years prior to the research interview with one participant having used AR in its early days in the early 1980s.

Table 10 Number of clinics used by individual research participants

One clinic only	19 (68%)
Two clinics	8 (28.6%)
Three clinics	1 (3.6%)

Snapshot of participants' service use

To explore what participants said about their service use it is useful to start with a snapshot of the duration of AR, the types of procedures experienced, the various impacts of service use – including impacts on the individual women (physically and psychosocially), impacts on partner and family relationships, impacts on employment and lifestyle, and ongoing impacts.

Duration

The duration of participants' service use ranged from less than one year to seven years, with three women being current users at the time of interview and five being undecided about ongoing service use. The majority of participants (77%) had used AR

for between two and five years. Most attempted two or three fresh and frozen cycles per year (69%). Ten participants (34%) had used artificial insemination and most (90%) reported that their partner's sperm was used; only one participant reported use of donor sperm and one participant reported using donor ova with her partner's sperm for several IVF cycles. One participant reported using pre-implantation genetic diagnosis (PGD); several women had tried ovarian stimulation-only cycles prior to IVF (20%). Seven women (24%) had used GIFT, twenty five (89%) had used IVF (fresh and frozen embryo cycles) and 17% reported that the ICSI procedure was also used in these cycles.

Currency of AR use

All but one of the participants (96.4%) had used AR services within the last fourteen years; half of all participants had used AR within five years of the research interview. One participant (3.6%) had used assisted conception procedures in the early days of AR in the 1980s, see Table 10:

Table 11 Currency of AR service use

Current or within last 5 years	14 (50%)
Within last 6-9 years	9 (32.1%)
Within last 10-14 years	4 (14.3%)
Within last 15-24 years	0
24+ years ago	1 (3.6%)

Proximity of service providers

Sixty-four percent of participants were able to access a clinic within approximately one hour's drive time (one-way) from their home and fifty percent of all participants had ready access to an AR service provider within their own home town or regional centre. Approximately one fifth of all participants (19.6%) had to travel between one and three hours one-way to get to their nearest clinic. Significantly, 16.8% of all participants travelled between three and six hours by car, one-way to access their service provider (see Table 12). This clearly demonstrates that for many participants substantial travel was required to use AR and the associated material and opportunity costs will likewise be significant.

Table 12 Distance to clinic (approximate kilometres, one-way)*

Clinic in same town	30km away	50km away	60km away	90km away	140km away	150km away	260km away	270km away	300km away	400km away	600km away
18** women (50%)	1 (2.8%)	1 (2.8%)	2 (5.6%)	1 (2.8%)	1 (2.8%)	2 (5.6%)	2 (5.6%)	2 (5.6%)	3 (8.4%)	1 (2.8%)	2 (5.6%)
64% within app. 1 hour's drive one-way					19.6% within app. 1-3 hours' drive one-way				16.8% over 3 & up to app. 6 hours' drive one-way		

*Travelling distances to clinics were calculated via *www.travelmate.com.au* and taken to the nearest multiple of 10 to minimise the likelihood exact locations being identified. ** Some women accessed more than one clinic.

Regional and rural context

In addition, given that rural and regional areas in Australia also usually have very limited public transport options, relatively high fuel costs and generally poorer road surface quality than urban areas (Cheers 1998) the access issues for non-metropolitan service-users are multifaceted. Many women had to factor in accommodation costs as well as significant travel costs in order to access AR services and several participants spoke of the added strain placed on them by the distances travelled, costs and safety concerns about driving too soon after procedures:

> *The travelling was exhausting... you can't just duck down to the clinic... It's not done locally so I'd have to drive... [over 100 kilometres one-way] ... and when you're on drugs and that you can't really drive properly anyway. (Kerrianne)*

> *After an egg pick-up you didn't really feel 100% ... you don't feel like sitting in a car for five hours. (Jenny)*

> *As they say – location, location, location! I don't think we would have succeeded...if there hadn't been a clinic [locally] then we would have done travel to [capital city over 400 kilometres one-way]...but I think that would have been a drag. (Ivy)*

> *The distance would be just impossible to try and cope with, with blood tests and ultrasounds and getting down for particular days. (Clarissa)*

Thus, for many women the difficulties of involuntary childlessness were exacerbated by a lack of reasonable access to AR services. This had led to decisions by a few participants (24%) to postpone their service use at some stage because of this locational disadvantage and 14% had discontinued service use altogether when they relocated to an area with no reasonably accessible clinic. For example, Judith spoke how location impacted on her access a clinic:

> *We couldn't do anything when we lived in [remote location]...When we moved to [metropolitan location] we used the local clinic. When we moved to [current large regional centre] we used the local clinic...I guess we were a bit late getting*

> *into IVF but it was very much depending on being in a location that offered IVF services. (Judith)*

Carmen spoke of her decision to discontinue AR due to access issues:

> *The amount of travel was just not possible. So it sort of crunched the deal at the end about more IVF... I probably would have done it had a clinic been here... It would have been nice to have one more go...He's an only child...It's so much money to outlay and to go to all that effort and hassle of going down there...You add the motel bills and things like that. (Carmen)*

Others also felt that long distance travel if attempted at all, could not be sustained for very long and some identified that long distance travel also impacted on time-off work, other family members, social commitments and lifestyle in general.

> *I remember thinking now I have to travel [over 100 kilometres one-way]... and I'm already in a fragile state and ...that maybe we'd missed our chance and that we'd never get to try IVF ...Because that was part of the decision – are we prepared to travel? What about days off? Will I work part-time? And financially, you factor in accommodation. (Marion)*

Modes of service delivery

Just over half of all participants used a clinic in their home town or within one-hour drive (one-way) from their home (see Table 11) and for approximately two-thirds of these women their clinic was operating as a satellite clinic. The remaining one-third of participants who used a clinic in their own town or within a one-hour drive used a primary regional clinic. For the women who travelled more than one hour's drive one-way, most (71%) accessed a metropolitan primary clinic and 29% accessed a regional clinic operating as a primary clinic. Of all participants then, regardless of travel time, two-thirds had mainly accessed primary clinics and one third had accessed satellite clinics.

Approximately one-fifth of the women who had mainly used satellite clinics spoke of access issues arising from the intermittent availability of AR services. Some felt they had rushed into their first AR cycle for fear of having to wait for several more months until the next clinic was operational, some felt the timing of their AR was not optimal and Felicity had specifically rural concerns about the inappropriate timing of her service use.

> *We did IVF at a really stupid time because we did it in the middle of ... harvest. I guess you get desperate and you really want to have a baby and you don't want to miss out on any more months and particularly because we are out here [on a farm] and they only do it three times a year. (Felicity)*

Kate spoke of having a 'minor complication' during one of her AR cycles at a satellite clinic and she was faced with the having to decide whether to abandon that cycle

altogether or travel to a metropolitan clinic several hours' drive away where they were equipped to deal with complication. Kate said that she 'didn't want to stop and start again' so she too chose to travel the significant distance so that she could continue that cycle. About one-quarter of these women however also spoke of distinct advantages of the satellite clinic model in that 'having four clinics a year is great because you can sort of pace yourself' (Ivy). These women felt that because AR cycles cannot be undertaken in quick succession anyway, that the intermittent nature of the satellite clinic was not a significant issue.

Other rural issues identified by participants included the often limited range of AR, health and allied health services offered in non-metropolitan locations. For instance, Marion had wanted pre-implantation genetic testing on her IVF embryos and could only access this service via a metropolitan clinic over 500 kilometres (one-way) away. Felicity's partner had needed a 'sperm wash' and because they had missed their chance to have it done at the last three-monthly clinic, they had to decide whether to wait another three months or go to a metropolitan clinic several hours' drive away. Others spoke of having limited access to general medical practitioners, medical specialists, counsellors and other health services. Several participants also discussed difficulties they had encountered as non-metropolitan users of metropolitan clinics. These issues will be discussed in detail in following chapters.

Other access issues identified by participants included limited access for most indigenous people, due mainly to financial and geographic access – 'it's not fair if access is not equitable' (Leonie). Felicity mentioned that a lack of childcare facilities in her area made it difficult for her to access AR when she was attempting to conceive her second child. Phoebe had experienced AR in the 1980s and had brought forward marriage to her current husband because at that time, AR was available only to married couples – 'we always intended to marry but we sort of felt a little bit pressured into hurrying the process'.

Financial considerations

Financially, access to AR can be problematic for all potential service users regardless of location. Even with Medicare rebates for many procedures, for most the financial impacts of AR use are considerable. This is compounded for rural and regional service users who have the aforementioned cumulative disadvantages in terms of rural economic downturn, travel, accommodation and employment impacts:

> *I've got a friend who has to travel ... [four hours one-way to the nearest clinic]... who's on IVF at the moment ...She's been trying for quite a few years but they've just run out of money... They can't afford it now. So they have to save up or get new jobs or something which makes it more difficult. (Jenny)*

Many participants expressed empathy for people who could not afford AR and spoke of how 'it must be absolutely horrific' (Amber) to have a fertility issue and not be able to access a service that might offer the hope of having a child. Leonie indicated ethical concerns about access to health services being dependent on ability to pay - 'you either front up with the money or...you think about that ethically' (Leonie) and Marion also felt that AR is 'a bit elite'. Belinda worried that single income families would be unlikely to afford AR – 'you just wouldn't be able to do it' (Belinda). With most AR clinics in non-metropolitan locations also being private health facilities rather than public health facilities, these access issues are exacerbated. These concerns echo the concerns of Corradi (2008), Pennings and Ombelet (2007), Roberts (2004) and others, in relation to social justice and equity in health care.

Even with relatively generous Medicare rebates in Australia, the financial impacts of service use were still described as substantial by almost all participants (97%). Most spoke about major financial impacts on life plans, including the postponement of house and other major item purchases, extending mortgages on the family home, selling investment properties, use of credit cards, savings and investment funds and borrowing money to fund AR. Felicity and her partner used funds from their managed investment account, money they had set aside as a source of superannuation for their farming partnership. Jan and her partner at the time were also trying to purchase a farm and had taken out a substantial loan for that. She said that they 'just got themselves further into debt' and spent 'many years paying it back' which she said was decidedly difficult in times of rural economic downturn in her area. Some participants said that they were 'working basically to pay for IVF' (Kerrianne). A few participants said that their household income was sufficiently high so that AR use was 'not a problem' (Ivy) but for most the financial measures they chose to undertake caused 'enormous strain' (Sarah) and some described 'crying buckets as you write out the cheque' (Carmen) especially for unsuccessful cycles.

> *We had to sell our house, which we never wanted to, just to keep going back on IVF. We maxed -out our credit card and we were really struggling financially ... but that's what it took, that is what it took! (Sarah)*

Many participants expressed appreciation for Medicare rebates and noted that even though not all procedures were covered and that there were gap payments on some procedures, that the Medicare refunds had been invaluable. The advent of the Medicare 'safety net' was a positive for many women and many also expressed relief that the original six cycle limit on Medicare funded IVF had been abandoned. Private health insurance also helped several participants offset the costs of service use. But despite the significant financial impacts and opportunity costs, many women said they would 'pay ten times over' (Kate) and that the costs were more than justified:

Yes it is a high cost, it cost us a lot of money, I don't see any way around that, I think it is a fact of life considering the science involved and whatever it costs to run a clinic... If it wasn't for IVF I wouldn't have kids. (Jane)

When we were in the delivery room Fred said to me 'this is the best money we've ever spent'. But at the time it seemed like such a lot of money for the possibility of maybe having a pregnancy. (Felicity)

It's worth it when you sit there and look at my child's cute little face...You wouldn't change it. I'd have much rather spent the money and have my child than be sitting here in a nice home with all the luxurious things around you, there's more to life than that. But I might have been a little bit miffed if we'd been through it all and ended up with nothing at the end of it. But that's the price you pay to give it a go. (Phoebe)

Given the considerable access issues and the reported stresses of being involuntarily childless, what was it like for these women once they started using assisted conception services?

Physical impacts on participants

All participants spoke about specific physical side effects attributed to AR at the time of service use or since AR use including: constipation, gum disease, nose bleeds and nasal soreness, bruising, weight gain, scarring from egg retrievals, breast tenderness, nausea, headaches, blurry vision, ovarian tenderness and swelling and cysts, ongoing menstrual irregularities, fatigue, abdominal bloating, and 'hot flushes'. The side effect most often reported from this range was headache, which affected approximately one-fifth of all participants.

Ovarian hyperstimulation syndrome (OHSS) was also experienced to some degree by several women (14%) and all of these women had used the same satellite clinic. They reported remarkably similar experiences of OHSS. They were all told to go home and manage this potentially very serious complication carefully themselves or it was managed in the clinic and hospital admission was avoided. Amber was so badly affected that she had to take two weeks' leave from work:

The clinic nurse coordinator basically told me to go home and rest, to only get up to go to the toilet, otherwise bed rest. She said that way it will resolve itself...She rang every day and asked 'you are not nauseous, you are not vomiting?' Just double-checking that I knew how serious it was, which really didn't do much to alleviate my discomfort...My ovaries would feel like rockmelons I was carrying around. (Amber)

Felicity was also sent home to manage by drinking lots of water and resting. She was told -

136

> *... this is really important otherwise I could end up in hospital on a drip and that kind of stuff and then...we went home and my husband didn't work for three days and I spent all that time in bed and he was force feeding me water...The nurse would ring each day and see how I was (Felicity).*

Kate's OHSS was initially managed at the clinic before being sent home:

> *My blood pressure kept dropping and I started not to breathe properly...I started getting really sick. They were almost going to ship me off to hospital, I think they should have done that a lot earlier but anyway they tried to make me drink... and they put a drip in me and hydrated me and I was better after that and ended up going home later that night. (Kate)*

These descriptions of 'in-house' management OHSS highlight issues raised by many authors and regulating bodies (e.g. Wang et al. 2008, p.51; ARTRC 2006) on the probable underreporting of undesirable outcomes such as OHSS. In the absence of a hospital admission for OHSS or other AR-related complications, there is no mechanism in place for recording such incidents and outcomes and the official data remain incomplete representations of many women's actual experiences of the technology. Surely this seriously undermines the evidence base of ANZARD and its stated purpose to provide evidence for the improvement in the quality of service provision? It indicates a need for further systematic investigation of such experiences to explore, *inter alia*, whether such responses are characteristic of certain satellite clinics or satellite clinics in general or whether there is a broader pattern across the whole sector in relation to adverse outcomes like OHSS.

Injections are generally part of most IVF cycles and other AR procedures and every participant spoke about injections, in particular their negative feelings about receiving injections and about the arrangements made to administer injections. Not surprisingly, many women said that they did not like injections, some described having a 'phobia' or being 'petrified' of needles. AR clinics often require service users to either self-inject or to organise their partner or someone else outside of the clinic, to administer injections. Fourteen percent of participants could not self-inject at all and 34% said that they could not self-inject initially but that at a later stage they had learnt how to self-inject through necessity, typically when alternative arrangements had broken down for one reason or another. For about one-third of these women, the fear of self-injection was overcome because they did not want their partners to have to give them injections or because partners were unwilling to give injections. Two women said that they chose to self-inject specifically because they 'didn't want to associate [their] partner with the pain of injections' (Felicity). In roughly equal proportions (one-third) partners were described as either unwilling to administer injections ('he couldn't go near a needle' - Sarah) or willing ('he actually liked doing it' - Elle) or neutral. One woman's partner was a health professional and so injecting his partner was not described as a challenge for him.

Where both participant and partner chose not to administer injections, other people were recruited including work colleagues, neighbours, local hospital staff and extended family members. A few were fortunate enough to know qualified nurses, either as friends or acquaintances and a few used their general medical practitioner or local health facility. Some participants (14%) described feeling unsupported by their clinic when they were learning to give injections or later on when they experienced difficulties with injections and this was strikingly apparent amongst those who had used satellite clinics:

> *I rang the coordinator and said I was having trouble with the injection and could I come down and see you guys and you do it for me. She said no, you will have to go and book into your GP. (Kylie)*

> *Fred was really worried... I was disappointed because I thought they would teach him how to do it like to have a practice session for him but there was none of that. She said 'this is how you do it, you pull this out here and then you squeeze it like this...Like I thought he would practise on oranges or things but there was no practice at all, it was just a demonstration. That's right. I was really surprised. I was a bit disappointed about that...I really thought he needed a bit more practice before he was let loose (laughing) ...It would give you a bit more peace of mind at least. (Felicity)*

> *I had some experience of giving needles but I still needed more than 'here you go now go away and inject yourself'. (Kate)*

Kerrianne said she felt that the necessity to seek 'outside help' with injections and thereby disclose her AR use to others outside her chosen circle of confidantes, had made her 'feel like public property'. While Amber had organised her neighbour to give the injections without disclosing their purpose – 'she didn't know what she was injecting me with or why at the time but yeah, she was fine with that'.

About one-quarter of all participants described side effects from injections including bruising, swelling, itchiness, redness and bleeding. A small number (7%) of all participants said they had experienced 'no ill effects' (Vikki) and that injection 'didn't hurt at all' (Elle) while others described their injections were 'very, very painful' (Ivy). Ivy also described her creative way of dealing with the injections; she would compare with other women 'how many time we say 'fuck!' when that needle goes in'.

In addition to the understandable displeasure associated with injections, many women described anxiety about 'getting it right' when giving the injections because of their importance in the assisted conception regime. One satellite clinic user was frustrated by her local hospital's perceived lack of understanding about the importance of the timing of injections and she was forced to wait for a nurse to administer an injection; another participant described her husband's uncertainty about giving an injection during the night:

> *One morning I remember he woke up and said 'we've forgotten your needle!' I said no we didn't, don't you remember? Were you asleep? He said 'Did I do it?' I am like yeah, because I remember, set the alarm, get up, get it ready, and he did it and I don't think he was even conscious. (Sharon)*

Emotional impacts

> *I am sure you've heard about the rollercoaster … (Sarah)*

All participants spoke about the emotional impacts of AR and as one would expect, a range of views, experiences and opinions were expressed and as illustrated by Sarah's comment, and in fact almost 50% mentioned 'the rollercoaster' as an apt description for the highs and lows and perhaps the feeling of being a 'passenger' in the processes of AR. Leonie described her experience as being '*like walking up a mountain I suppose; there were lots of highs and probably more lows'.* Whereas Lindi described a more positive experience overall:

> *The first word that springs to mind is empowering...I think it can be a very positive experience even though it is difficult and emotional and everything. (Lindi)*

Seventy-two percent of all participants reported feeling 'moody' during active use of AR. 'Emotional swings', 'crankiness', 'aggressiveness', 'depression' and 'anxiety' were identified in particular. A few also reported feeling 'confused', 'drained and sleepy' and 'not being able to think clearly':

> *I was that numb and even when I think about it now it feels grey - cloudy and grey. (Elle)*

> *I was really spacey...There might have been times when I felt a bit gooey but just more spaced out and not feeling right...you just have this wishy washy weird, surreal feeling for a couple of days...just spun out...I remember being at the supermarket and I was having trouble thinking what I was doing...I was struggling to think. (Jane)*

> *You couldn't drive properly...I couldn't even put petrol in my car properly because I'd look at the litres instead of the dollars and get confused and it really affected my thought processes...And when you're trying to get on with everyday life it makes it really hard. (Kerrianne)*

Two-thirds of participants spoke about the 'intensity' of AR and of it being unremitting and thereby difficult to cope with and some felt they had withdrawn from a lot of social contacts due to anxiety about how their emotional state was impacting on others. Marion felt that her 'whole demeanour changed' at some points in her AR cycle and many spoke of AR use as being 'an obsession... totally life-consuming' (Kerrianne). As a counterpoint to this intensity, one-third of participants said that AR 'just fitted it in' (Josie). Some commented on the regimentation that AR brought into their life and

139

Jane felt that her decision-making capacity was diminished because 'the future was not there' and several women spoke of feeling 'very programmed':

> *Time marched on ... I wonder how much of my life just flew by; it was all so programmed and scheduled. I mean we even went on holidays at the right time ... I think you just regulated the way you felt depending on what day of the week it was and what time of the month it was. (Sharon)*

> *I've been counting days for six years you know. (Clarissa)*

Almost all participants said that the waiting time between embryo transfer and pregnancy test was the most emotionally trying time of all –'unbelievable torture' (Clarissa). The two weeks leading up to embryo transfer were seen as more active, constructive and hopeful while the post-transfer time was spoken of consistently as 'horrible', 'stressful', 'awful' and as 'the two-week demon' (Sharon):

> *They are the longest ten days I think I have ever experienced in my life. (Amber)*

> *It was like a big down when it didn't work, very depressing. (Belinda)*

> *A failure is very, very sad... But that's probably the worst day, the day my period would come. (Carmen)*

> *You don't want to go to the toilet you are that scared. (Elle)*

> *Trying to live a normal life in those two weeks was just ghastly. (Ivy)*

The unsuccessful cycles, marked by a negative pregnancy test and a menstrual period triggered a grieving process for most participants:

> *I'd cry, have a few drinks ... lots of tears ... You are probably on a downer for a week or so, you know really down for a couple of days and then you gradually pick yourself up and out of the depths of depression and get on with life and get going again. (Phoebe)*

Carmen spoke about her anger after an unsuccessful cycle of a cathartic experience:

> *You know how it's supposed to be bad luck to buy anything for the baby before you are pregnant? Well I'd saved all this baby stuff and I thought, no. And I ripped them all up. Tore them to shreds. I think Cam thought I was going mad, but honestly it was great! It was such a relief. I just got it all out and I felt a million dollars after that! (Carmen)*

Impacts on self-regard

During the research interview all participants were asked to comment on the impacts of involuntary childlessness and AR on their view of themselves as women. Virtually all participants offered negative self-assessment as the result of involuntary childlessness. Carmen said that it had eroded her self esteem and that she felt embarrassed, several

said they felt 'less of a woman' and 'not normal' (Jan) and others described feeling 'incomplete' (Judith) or 'barren' (Marion). Some described feeling betrayed by their own bodies and/or by life circumstances:

> *I don't think it was the procedure that failed I truly think it was my cycle; you know the whole body thing broke down. (Vikki)*

> *I remember being told that my body wasn't compatible with the transfer and so therefore my idea of that was that my body wasn't doing the job that it should have been and so therefore I had failed personally, yeah... OK I have just failed that one... I don't think they meant it that way but it made me feel like I had personally failed... I don't know why it hadn't worked because when you asked they didn't know either. (Leonie)*

These experiences indicate that women may often experience technological failure as personal failure. On a broader scale, this serves to reinforce the 'faultiness' of women as 'patients' and to reinforce the image of technology, particularly this as biomedical technology, as somehow superior and science as father (Lie 2002). It also reinforces the existing guilt many women described about involuntary childlessness in the first place and these feelings of guilt seemed to rest, or were placed firmly with the women and rarely on male partners, as described in the previous chapter and further illustrated below:

> *It just reinforced the guilt. I always felt it was my fault that we could not get pregnant even though it was unexplained. It was just like somebody grinding a knife in your back, into your heart, saying 'well it's your fault... You are a female you should be able to produce children'. ...You try to evaluate all aspects of your life and say well there has to be a reason here somewhere, what is it? ...Try and work out why it is not working. (Sharon)*

> *The technology is there... and it's like me, it's me, that's all I felt. (Tina)*

Sarah spoke of the effects of being labelled 'infertile' and how her eventual pregnancies meant that she no longer had to be one of the 'others':

> *...I don't have to be an infertile woman anymore and that was the kind of label you give yourself or they give you or something, I don't know, you just become an infertile woman... I am normal now... I am not one of those people. (Sarah)*

Some women however, even after successfully overcoming involuntary childlessness still described themselves as infertile – 'I'm infertile' (Jenny, mother of two babies via AR). This indicates the power of involuntary childlessness as a life crisis and how in terms of identity, that the label can prove difficult to shake, a phenomenon discussed by Koonin and Napier (2000).

Impacts on partner and family relationships

It tears you apart or it brings you back together. (Phoebe)

Participants identified a range of positive and negative impacts on partner and family relationships. On the positive side, almost one-third of the women said that their experiences of involuntary childlessness and AR had brought them closer together and that 'if a marriage lasts through it, it will last forever because it's not an easy time' (Carmen). Many commented that AR made them 'work together' and to communicate more directly about intimate aspects of life:

> *It didn't push us away from each other, it probably brought us closer together and ...I can talk to Lewis about anything and it wouldn't faze him...If there was a problem we would be able to work through it together. (Leonie)*

Slightly more than one-third (34%) spoke about the negative impacts on partnerships including the 'mood swings' experienced by many women and the anxiety felt by some women about sexual intercourse during active use of AR services. Twenty percent of these participants' negative comments related to 'nervousness' about having sex with their partners, in particular the necessity to time sexual intercourse and the strain this placed on their partnership. In addition to sex losing its spontaneity, some women spoke of losing the spiritual, intimate side of sex as well as it becoming a mechanistic, 'clinical' task and of this potentially having a long lasting impact:

> *I am sick of being constantly up and down, up and down and him saying you never want to have sex because it's not the right time or I just don't feel like it or whatever. It becomes an issue because sex is for babies and not for anything else and it is very programmed and ... I don't feel like it but we have got to do it... It is really very difficult ... And I think it has ramifications for years, it really does. It takes a lot of time to get back to what you had...to how it was before you got into that cycle. (Sharon)*

A few women spoke of their partner's involvement in AR procedures and again, the impacts of this seemed to be mixed; a few said that more direct involvement from their partners enhanced closeness and provided support, for others, some sorts of 'involvement' caused more negativity, blurred boundaries and undesirable associations:

> *He would come home just to give me the injections and ...I started to really dread him coming home because I knew I was going to get an injection. I started to get panicky because I knew he was coming home...So I taught myself how to do the injections because I just didn't want to have that association with him. (Felicity)*

One participant felt that her first marriage had broken up primarily because of involuntary childlessness and a lack of success with AR. Another participant said that

she was aware of several marriages in her circle of acquaintances that had broken-up 'because of the stress of it' (Phoebe). Some discussed their need for support from their partner but also recognised that their partner had their own support needs and was dealing with their own grief:

> *Your husband has his own grief as well but you just wanted him to support you, that was awfully hard for him. (Sarah)*

Women who had used AR for secondary infertility also identified impacts on their older children and some felt that their children should not have been exposed to some aspects of AR such as ultrasounds, injections and blood tests. Often a lack of childcare options was cited as part of the problem along with the use of general health facilities and high demand for health limited health facilities in regional areas:

> *It was a rigorous schedule particularly when my son was little. He was two when we started dragging him around to blood tests and finding somewhere for him to go without family support here in town, for ultrasounds, because he didn't need to see that. ...Waiting up to two hours for blood tests with a two year old is not fun...He still has his own needs...He is insistent I interact with him and he knows all about needles, coming to have blood tests with Mummy. So he has learnt a lot more than he perhaps needed to. (Clarissa)*

Impacts on lifestyle

Putting plans and decisions on-hold while using AR was mentioned by many participants. Uncertainty about the future and whether a child was going to figure in that future prompted a 'decision-making rut' for some (Jane). Over two-thirds of women spoke of having to accommodate AR procedures around work commitments and of often having to take leave from work to do so. For some this was a huge strain that had impacts on income and job satisfaction and possibly on promotion prospects and opportunities. Some spoke of work being a 'saviour' in that it provided a distraction from the intensity of AR. A few women enrolled in further education so that there would be 'something else in my head' at the time of service use and 'something in my life' if AR failed to result in the birth of a child (Jane). Some used their weekends, when possible, for AR procedures rather than disrupt their paid work while three participants resigned from their jobs to focus on AR – 'I don't think I could have worked while I was having all those drugs and all that' (Kylie). Tina said that she transferred into a different department with a less demanding workload because she knew that she would need significant time-off work to accommodate AR. For those whose jobs involved travel, there were some additional challenges in combining paid work with AR:

> *Since I left that job, someone told me they'd wondered whether I was snorting coke because with the hormone you actually sniff some of them ... and I was sniffing this stuff which caused nosebleeds and a red nose and this*

so...(laughing) ...It's not the kind of thing you tell everyone... And my job involved some travel and my boss was always wanted everyone to share hotel rooms and I'd say no, and I think he thought I was a snob but you know I'm not injecting myself in front of other people, and always bringing stuff with me... He was never happy about it but he wasn't the sort of person I could have told. (Jacquie)

Sarah's work also involved some travel and she said:

I can't be two or three hours away from where I am meant to be having the [egg] collection done. And the time I did inject myself I was going to a conference ... so I had to leave at 5am and still do that in the morning... It just adds another dimension to it. I had to tell my boss because ...some meetings were compulsory and they always seemed to coincide with a day I needed to go so I ended up having to tell her. (Sarah)

Some women chose not to disclose AR use to their employers or colleagues, as Jacquie's comment illustrates, choosing instead to try to adapt work practises to fit in with AR service use. Amber for instance was often concerned that her repeated lateness to work would affect her job – 'there are only so many times your car can break down in a two week period!' She managed to 'get away with it' but stated that she found this 'stressful'. Some others did inform their employers of their situation and most said that their employers were generally supportive and able to accommodate some flexibility into work patterns when required. Anne and Belinda's supervisors had also experienced involuntary childlessness and said that their supervisors were empathic.

AR affected the quality of leisure time, holidays and lifestyle more generally, nearly one-third of participants spoke of having to schedule holidays around AR cycles and of having to adapt the routines of medication, injections and tests:

Our first holiday ...I took all these drugs...How am I going to explain all these syringes in my bag? ... (laughing)... All these syringes and little bottles of white powder and stuff like that... So we took all this stuff with us, I'm thinking this is bloody ridiculous, here we are on holidays and I am going 'time for another needle', which wasn't very nice. (Sharon)

Amber also spoke about having to 'sneak off and have blood tests' during one of her holidays. Others used their time of involuntary childlessness to travel and saw this as 'one bonus that came out of it' (Carmen) but added that during active AR service use, the focus was on AR and little else.

Kylie and her partner had been saving for a holiday and then chose to use the money they had saved to fund their AR procedures instead – 'so at least we didn't have to borrow the money' (Kylie). Jacquie was able to combine leisure and AR service use as a result of her secure financial status:

All our money went on IVF and holidays; we didn't care about anything else (laughing). (Jacquie)

However not all attempts to combine the two were successful; for example, Carmen's holiday with family had come to an abrupt end when an IVF cycle failed:

...the cramps started and I couldn't even say why, I just had to go, I couldn't even say goodbye. I just had to walk out, just couldn't deal with it. (Carmen)

Ongoing impacts and concerns

Just under half of the participants expressed ongoing concerns about AR use especially in terms of the possible long term effects of pharmaceuticals used during AR on them as well as possible ongoing effects for offspring conceived via AR. Some said that to some extent they had withdrawn from family and friends during active use of AR and that it was 'hard to get back' (Vikki) to the same level of intimacy and connection with significant others, even several years later, as a result.

Jan, who used AR in the early 1980s, spoke of having to sign a waiver because of the experimental nature of IVF at that time. Carmen also expressed concerns about the drugs used during AR – 'you can't use that amount of drugs and not have some repercussions'. Clarissa also felt that the long term effects are 'unknown' and 'in ten years' time, who knows what they will have dug up?'. Phoebe spoke about her ongoing health problems including persistent cysts on her ovaries, 'cysts on my voice box and my thyroid gland and a few cysts on my back'. Phoebe said that while her family doctor knew she had used AR, she did not think he would 'go back and make any correlation between issues that I might be having now and it being an effect of IVF'. Some also expressed ongoing concern about their 'IVF babies' and whether assisted conception had caused any long term issues for their children and spoke of this concern as 'something that's always in the back of your mind' (Felicity).

In terms of ongoing psychological and emotional effects, a few women indicated that they felt that their privacy and integrity had been impacted upon by their AR experiences:

I'm a veteran... So when you have someone looking down there, you know, that area just doesn't worry me... I went to one doctor [after AR] and I'm taking off my clothes to put the gown on for a Pap test and she said 'Have you had children?' and I said no, and she said 'Oh it's just the way you know you are not giving a care about all this' and I said I've been through IVF and I've had that many doctors look down there and she's like 'Oh that's good'. (Lily)

I never had anything done like that before and being quite a private person and keeping very much to myself it was just a lot of people poking and prodding me...People having to do stuff...So that was more embarrassing I suppose than anything. (Toni)

These comments could be seen as reflections of ontological choreography (Thompson 2005) to AR procedures and women's agency in negotiating these processes with medical personnel. However it could be argued that these experiences are more akin to capitulation and to women falling into line to dance a series of steps already invented by choreographers with much more power and influence than the women themselves. This underscores the absence of women as active agents in the biomedical context of service provision.

The language of AR

Much of the terminology used in AR by practitioners and clients alike reflects the dualism and fragmentation of the reproductive process. Body parts and medical procedures take on objectified, mechanistic, and / or commercialised titles; ova are 'harvested', 'produced', 'retrieved', 'collected'; sperm is 'banked', 'deposited' and also 'collected' (as in Seguin 2001). Semen and more specifically sperm were often humanised as 'the boys' or 'little fellas' while ova usually being dehumanised and referred to as 'eggs'. Some women even referred to themselves as 'chooks' or 'good producers' and similar terms:

> *It was a good harvest for my age, apparently. (Toni)*

> *I was only ever getting five or six eggs so I was never a really good chook. (Sharon)*

> *I think it was about eight or nine eggs they harvested – oh that sounds awful! It makes you sound like, I don't know (laughing), it just doesn't sound right – harvesting fruit or something! (Jan)*

This sort of objectification is a recurrent theme in feminist analysis, for example from Klein's first wave feminist work (1989b), to Greer (1999) and to Rapp (2001), and others, as a reflection of the broader oppression and commodification of women. Further, the experiences often reported by participants in this research indicate that feelings of detachment and disembodiment from the processes of reproduction are still too dominant in AR.

Notwithstanding the highs and lows of the experience, the overarching message from these women is that AR is a valued option for those wanting to redress involuntary childlessness, but that all too often services are not delivered in the most positive way.

To explore this and other themes in greater detail, the participants' views on AR clinics, their perceptions of clinic staff and the way services were delivered are discussed in the next chapter.

Chapter 10 - Experiences of service provision

The previous chapter established that approximately two-thirds of participants had used primary clinics and one-third had used satellite clinics and that for many women, travel and associated service-use costs had exacerbated the existing psychosocial stresses of involuntary childlessness. Given the high level of service-user motivation and the associated costs and impacts of service use, how do these women perceive the quality of the service they received? Does the nature of service delivery reflect the huge investments made by women and their partners? Is there high quality, client-centred service provision based on a deontological approach? Are women generally treated as active participants, as unique moral agents in assisted conception clinics?

This chapter shifts the focus of discussion from the specific personal and family level impacts of service use to this broader level of service provision and explores what women said about the nature of the clinics they used and the service providers. In particular a range of issues concerning staff behaviour, privacy, clinic facilities and aesthetics as well as experiences of medical procedures will be presented.

Perceptions of clinics

> *It is not just a physical procedure. It is very emotional, you know... I think there is a real difference in that. They set you up on the medical side, they set you up for what to expect physically ... but they don't tell you it's normal to cry for two weeks out of four for some people, for some people it might be four weeks out of four or it might be for a day. They don't explain that part of the process and I think it's important. I am sure it is... It wasn't just a scientific, biological process; there was more feeling to it than that. (Sharon)*

> *I think for a lot of people it is very clinical. Clinic is the word. It is a science and that is, I guess, the best way of saying it. It is science and that is it. If you get a living, breathing baby at the end of it – yahoo. If you don't, you have to walk away. Yes, there is not a lot of humanity in it I guess. You have to find that for yourself and that could make or break some people... It is very invasive. (Jane)*

These comments are representative of many participants' statements about their experiences of reproductive technology. Many, though not all, felt that their psychosocial needs had largely been neglected and some even felt that they had not been treated as individuals with individual needs. A few women mentioned positive experiences and a common thread running through these comments related to the times when they felt validated as individual women and not as generic 'patients':

> *My own doctor phoned me ... you know a bit of a chit chat, how are you going, and like – you care! You've taken a bit of time out of your day to see how I'm going. So that was good, but that was it. Usually, unless I phoned him, there was no contact. A lot of the contact was on our part. (Marion)*

Some participants were clear about wanting to affirm their consumer rights and to demand an adequate standard of service:

> *They had so many patients to think about and everything but the bottom line is ... you are spending a hell of a lot of money and I think they owe it to you to make a greater effort. It is a very expensive procedure and therefore you should get your money's worth. (Lindi)*

A few had actually taken action to assert their rights, with varying responses from their clinic. Felicity described a positive, constructive response to feedback she had given to her clinic about her perceived need for better staffing at the clinic – 'they actually took it seriously and followed-up, I was really pleased about that... They did take it on board'. Marion however had provided feedback to her clinic on the clinic's own evaluation questionnaire. The evaluation form included an option for 'further contact' or 'no further contact' in relation to the information provided by service users on the form. Marion opted for 'no further contact' but this was breached when the clinic's doctor telephoned her to engage in a rebuttal of the comments and complaints about the clinic's service contained in her evaluation:

> *I was quite embarrassed that he was quoting things that I had said at a very delicate time of my life... and if I had known he was going to phone I might not have said the things I said, so he really turned me away from ever going back. (Marion)*

This type of breach in research and service delivery ethics could be a reflection of the often uneasy balance between AR clinics as service delivery agencies in consumerist times and traditional medical model approaches to treatment, whereby the patient is ideally compliant and passive. The inadequacies of a predominantly biomedical approach to service delivery in this context are highlighted, particularly in terms of women's rights to be regarded as active moral agents within a broader societal context.

Many participants described feeling 'like being in a cattle call' (Sarah) and being treated 'like a number' (Clarissa) and of generally being treated 'impersonally' (Kylie) and this seemed to be especially so for women who had used satellite clinics. The 'cattle call' and 'cow' imagery used by several participants mirrors Klein's (1990) findings on depersonalisation in clinics. The satellite clinic model of service delivery and its emphasis on throughput in a limited time frame could mean that women using these clinics are especially prone to being treated as universalised, standardised objects rather than as active participants in the processes of AR. The impersonal approach however is not confined to satellite clinics in non-metropolitan areas; depersonalisation was also a factor for some of the women who had used a metropolitan clinic at some stage. Some however contrasted their metropolitan experience with their experience of the regional clinic in favourable terms:

I don't even know if you really had a number [at the metropolitan clinic] but it felt like you had a number (laughing)... The [regional centre] clinic was much more personal, a lot more intimate and that was a better experience. (Sarah)

You were a number on a list... at the [metropolitan] clinic we were a number. Even in the waiting room you were called by a number not a name. Whereas here [regional centre] you became Marion and Max... They were interested in us as people, not patients... we weren't just another statistic...They were genuinely interested in the issues that we were having and working together, working for us to try and find solutions and not just pushing us aside. (Marion)

Based on their comments, these women would clearly prefer to be respectfully acknowledged as individuals and with sensitivity and human dignity. Marion specifically rejected the 'patient' role and indicated her need for a consultative, collaborative approach to the provision of assisted conception services. The need for the mutuality of relationships to be recognised in the reproductive medicine encounter is abundantly clear.

Experiences of clinic staff:

Participants clearly identified the importance of clinic staff having effective interpersonal communication skills and a thorough knowledge of clinical procedures. In addition to these attributes, service users were also looking for personalised, reassuring, and above all, respectful treatment as unique individuals and the presence or absence of these factors appear to be key influences on their view of AR experiences. Phoebe for instance said that the nurses at her clinic were 'fabulous', specifically, that they knew her by name and treated her 'not as a patient but as a person'. Jacquie also identified the importance of staff using clients' names and she commented on how reception staff at her clinic had behaved in a manner that made her feel that 'they weren't interested'. Jacquie further commented that in the context of being a client using assisted conception, service use was 'such a huge thing for us and to them it was nothing'. This procedural or technical approach to AR service delivery at any stage in the process is clearly unsatisfactory.

Feeling welcomed by reception staff upon arrival at the clinic was also identified by Vikki as important. She had a more positive experience based on staff's friendliness, warmth and the feeling that staff 'were really there for you':

… it didn't feel like a clinic when you walked in, you didn't feel like you were going into a laboratory… it was really quite warm and inviting so that made a big difference'. (Vikki)

Lindi and Carmen also spoke in very positive terms about their respective clinics and the 'caring support' (Carmen) and the 'great feeling' (Lindi) they had experienced from staff. Carmen mentioned the importance of touch and discussed how holding hands

149

with attendant staff and supportive 'pats' on the shoulder had been much appreciated supportive gestures. Likewise Lindi said that 'you get big hugs' when there had been positive outcomes and that this too had been very positive and humanising physical connection for her. These examples of touch and physical contact could be seen as actively blurring the boundaries of the traditional medical model's roles for patient and staff and as evidence for how service users can positively experience open acknowledgement of the transactional nature of the medical encounter in this context (Shildrick 1997). For these women, these gestures acknowledged personhood and connectedness and in some way restored a degree of human intimacy in a clinical setting to the personal experience of the conception of a child.

The clinic coordinator

A key person in the whole AR experience is undoubtedly the clinic's coordinator, and in this study, the coordinator was typically a nurse by profession. All regional clinics used by participants had a sole coordinator and most of the metropolitan clinics had more staff. For some the small-scale regional clinics meant more continuity in service and if you had a good relationship with the coordinator, all was well. If however the relationship between client and coordinator was not positive, this had a significant impact on the experience for those participants. The following comments illustrate both ends of this spectrum with rapport between coordinator and client being a key factor:

> *We couldn't get any sense out of her...she was really detached and not warm, you didn't get the feeling that she cared and that the feeling was you were just a number, another IVF person...It was very difficult, everything else was fine...What can you do? There is only one coordinator here, there are no options. (Kate)*

> *The coordinator was fantastic. She was dedicated and genuine and would go out of her way to help me. (Carmen)*

Another participant (Elle) said that she felt 'judged' by the nurse coordinator and Jane, like Kate, felt that she had been treated as a generic 'IVF person' and that it 'never crossed the coordinator's mind that I had a life outside IVF'. From this it appears that ontological choreography as a means to manage AR is effective enough when the woman herself chooses to suspend personhood, say, during clinical procedures, but having a third party behave in a manner that robs you of personhood is undesirable. Indeed it seems all the more important for the non-clinical aspects of AR to be managed in sensitive, personalised ways to offset the clinical, procedural side of AR.

Medical practitioners

Along with the clinic nurse coordinator, the medical practitioner is another key player in the AR experience. The majority of medical practitioners in this study were male and

all participants offered information about their doctor during the research interview. Again as one would expect, there was a variation in opinions about the quality of care and the communication skills of doctors, but a pattern of dissatisfaction was clear in the participants' comments about this particular aspect of their experience overall. Almost 60% of responses were negative, just over 30% were positive and 5% were mixed and 5% did offer specific information about their medical practitioner. Some descriptions of doctors included 'business-like' (Sharon), 'wonderful' (Phoebe), 'strange' (Jane) 'lovely' (Carmen) and 'horrible' (Jacquie).

Many comments about medical practitioners reflect the biomedical focus of AR and the neglect of psychosocial aspects of assisted conception and involuntary childlessness. Many women's comments identify the dualism upon which the medical model in general depends and their comments highlight how unsatisfactory this is for many service users. The technical proficiency of some doctors was noted even if it was in the absence of effective communication skills. These themes emerging from participants' comments reflect Peddie et al.'s (2005) findings that service users in fertility clinics are often disappointed by their treating doctor's apparent lack of compassion and detachment. The selection of comments below reinforces the message that disrespectful or objectifying treatment serves to exacerbate the dissonance of the whole experience.

> *It really felt like the clinic only gave you the medical point of view and the medical side of it...The doctor isn't a very empathic bloke, it is just, you know, pretty business-like... It was not nice to think that that was what you had to do to get a baby when it wasn't supposed to be like that... He is very good at what he does; he probably can't afford to get emotionally involved. (Sharon)*

> *He is a strange fellow... He is a businessman and that is what it is about for him. I think there are more sympathetic lawyers! I just found him abrupt and horrible but you are just a number, his next patient basically and there will be another patient after you. It's really up to the nurse to offer some humanity; there isn't a great deal of it. (Jane)*

> *I don't believe he's the right person to run an IVF clinic. (Kylie)*

> *Horrible... no bedside manner... I often wonder what he's even doing helping women because he's, he's, oh I don't know... He takes an abrupt manner so that he doesn't get involved, he doesn't want to get emotionally involved but he's very abrupt, probably even rude I think. I used to think' gosh, I hope we don't see him today'... I don't think he likes women. So I think it is an odd career choice for somebody who is a bit of a chauvinist to be doing the job that could change the life of someone. But... he must be good at what he does...But I thought 'you're an idiot' because we're sitting here thinking 'what a dickhead'. (Jacquie)*

> *He hasn't got the best of bedside manners...You'd just see him and he'd say*
> *'what are we doing here?' and then his support staff would take over. (Judith)*

These comments illustrate the recurring themes of medical practitioners' emotional distance and how many service users acquiesce to 'dance' in accordance with the medical model approach in order to achieve the desired outcome. These comments also show some of the means used by women to reclaim personhood via internal dialogue and assessment of the doctor's behaviour. Jacquie's comment is testament to her refusal to be excluded as an ontological agent.

Another example of psychosocial and spiritual aspects not being taken into account comes from Kerrianne who held strong religious beliefs that conception should not occur outside her body and in order to accommodate her beliefs she had requested that only GIFT or artificial insemination be used. Kerrianne however felt that her doctor was more interested in using IVF and that he was unenthusiastic about GIFT and disinterested in her preferences:

> *The doctor basically told me that it wasn't his problem and that I was the*
> *biggest moral dilemma he's come across...He wasn't interested in where I was*
> *at or how I was feeling...He basically told me that it wasn't worth the worry or*
> *time...'You're going to have the procedure or you're not', which is fairly blunt...*
> *Every time I tried to bring it up again there was a kind of a roll-the-eyes... you*
> *know – 'we're actually here for this and not that kind of thing'. But they're*
> *important parts of who I am. (Kerrianne)*

Kerrianne described her overall experience of AR in negative terms and largely attributed this to her reluctance to accept 'treatment' passively and to her continued efforts to advocate for herself according to her spiritual beliefs. Kerrianne believed that her feistiness and persistence in directly debating these issues with the doctor meant that she became a 'difficult patient' and her whole experience of service use at this clinic was thereafter defined in this way and her views and needs were not recognisable as legitimate. The 'difficult' patient' poses challenges to the biomedical approach and Kerrianne's experience also highlights the inflexibility of the medicalised approach to conception, her ontological exclusion and the refusal to respect the transactional aspects of assisted conception. Using Thompson's (2005) concept of ontological choreography, it could be said that Kerrianne had tried to have some input into the 'dance' but had been told in no uncertain terms to fall into the strict routines of the choreographed line or to exit the dance floor. She eventually chose to get off the dance floor.

From the following selection of positive comments it is clear that rapport, genuineness and a caring attitude make for much more ethical service delivery and for a more satisfactory experience overall for service users:

[Doctor's name] is a wonderful person. He's very straight up and down, he tells it to you straight...He was a good support...He would chat to you on the personal side of things. We knew him personally and he knew us. (Phoebe)

He was lovely...he would have a joke with you, you know sort of lighten the mood a little bit. (Carmen)

A fill-in doctor did an egg retrieval for me once and when I came out he actually drew where all the eggs came from and the sizes, like he'd done these little circles and diagrams and everything and on the bottom of the note he drew a happy, smiley face and wrote 'good luck!'. And I thought, for me, that's great. (Jacquie)

These comments not only illustrate how being treated with respect as an individual has a positive impact on the experience of service use, but also how direct acknowledgement of the purpose of the clinical procedure - the conception of a much-wanted child – also adds to the experience. This blend of technical proficiency, professional communication skills and human warmth appears to be ideal in this context.

Along with a personalised approach to clients during clinical procedures, another important aspect of AR practice is respect for the dignity and privacy of service users. Almost 90% of participants commented on privacy in relation to their service use and from these comments, one satellite clinic located in a regional centre emerged as being particularly neglectful of their clients' privacy during procedures:

There were three or four other people in there... I thought there would be the doctor and one other person but yeah, there were quite a few people in there and it wasn't a huge room and with four or five people in there, like they all introduced themselves and said why they were there... Well I just sort of figured they've got to be here. There was nothing I could do about it; I just had to bear with it. (Josie)

I have never been in there with just the doctor, there is always a crowd, so you lose your dignity, lose your privacy, you just look at the screen and think of something else. (Clarissa)

It was almost an out-of-body experience, where I couldn't let myself get too involved... I was too busy trying to handle the uncomfortable-ness of it all... He just said 'hop up on the table we are going to give you this injection' that was about all...he didn't talk much at all... We hadn't met him before so we didn't know his name. (Elle)

One doctor came in while I was getting my eggs taken and he was just standing there talking and talking about doing the procedure to the others. I don't know this doctor. The door was open. I just think it was very unprofessional. I mean that was probably just a one-off case, but it was very uncomfortable for me, just the whole feeling of getting the eggs taken it was quite painful. I just thought there should be a sheet over my legs. (Kylie)

153

> *There was a cast of thousands in there with me with my legs in stirrups and the spotlight on my privates and I was just totally unprepared for that…Then I had, without my consent, which really irked me, I had the other gynaecologist pop in and see how things were going. I wasn't even his patient, he was no-one to me. I had to figure out who he was after the event…He didn't introduce himself…He was probably thinking 'just another cow in the procession'… I was quite offended… I didn't feel comfortable saying anything or whatever… In terms of privacy and dignity I think that could have been handled a lot better. (Amber)*

Amber, Kylie and Elle's comments in particular demonstrate these medical practitioners' lack of basic professional communication skills, lack of respect for clients as well as a lack of appreciation of the purpose of the service and the importance it might hold for clients. To dispense with introductions, not bothering to close the door of a treatment room and not addressing the issue of observers is fundamentally disrespectful. This mechanistic approach to AR at this particular clinic led all of these women to actively disengage from the process of assisted conception – literally Elle's 'out-of-body experience'. The doctors' approach was not humane and the women's personhood was unacknowledged and rights to privacy and dignity were neglected. It is important here to emphasise the context of these experiences in this clinic; specifically that satellite clinics operate only intermittently and that women's cycles are synchronised so that the specialist practitioners travel to the regional location to deliver specialist procedures within a very limited time frame. In this context then, it seems that at this clinic at least, a norm may have developed whereby the throughput of women was prioritised over quality of care and ethical practice. It is disturbing also that the presence of observers in this context was not explained and informed consent presumably not sought or given. Such lack of professionalism and dehumanisation of service users could send undesirable messages to observers about 'acceptable' practice and thereby perpetuate such practice in unreflective observers.

Jenny, who had used a different regional (primary) clinic, also experienced a similar loss of dignity and a lack of consultation about those present during procedures:

> *You have to do a lot of embarrassing things like sit there with your legs up and all these people come in and there's no privacy. The doctor, I guess he sees it every day, he just says 'sit up here, do this'. (Jenny)*

The sort of dissociation described above should not be necessary to cope with 'treatment' at any type of health facility. Lily described how her experiences of AR had led to her desensitisation to intimate examinations and how her strategy of disengagement had become generalised from AR to other health contexts:

> *Having doctors look at your insides... that sort of stuff doesn't worry me, like going for a Pap smear anymore, that's for sure... You can't be shy about that sort of stuff... I'm a veteran. (Lily)*

Some participants further commented on their doctor's and other clinic staff's lack of empathy and respect during AR:

> *I don't really think male doctors can have an idea of women's heads and... how consumed they are with their bodies and whatever... Guys really need to be sympathetic with women – not being 'poor women'... I think there is ignorance about women's lives that I think needs to be examined. (Jane)*

> *One male nurse was putting a lot of pressure on my stomach [during an egg retrieval] and he would be right over the top of me pushing down and he said to my partner 'your wife must have a particularly high pain threshold because most women would have passed out by now'... That particular person did make a lot of comments when he was doing things, not complimentary comments a lot of the time...He was never known for his bedside manner... It seems strange that he'd gone into a profession not having the bedside manner to go with it. (Phoebe)*

> *The doctor, he said to me 'it is only going to be like a Pap smear'... I got quite cranky and said well have you ever had a Pap smear? (Kylie)*

> *I have worked with a lot of specialists and I think it just goes across the board... just a little bit too casual about your personal condition, saying things like 'huh, I didn't realise you were such a mess inside' or 'if I were a gambling man I'd bet that you wouldn't get pregnant naturally'. I don't know, very casual things about something that is so acutely personal to you… I was there with my legs up in stirrups with him telling jokes at the other end of me while he is doing the transfers and stuff… His manner was just very unprofessional. (Sarah)*

Kylie's comment illustrates the importance of experiential knowledge and her assessment that the practitioner in question lacked the requisite knowledge to reasonably make such a comment. The quotation from Phoebe shows that while the nurse was in one sense acknowledging her individuality (that she had not lost consciousness) that in only addressing Phoebe's (male) partner, he was reinforcing her object status as a passive patient – she is 'not there', he has choreographed her out of the scenario - she is not afforded ontological agency (Shildrick 2006).

Interestingly, one participant with a professional background in the hospitality industry assessed the medical profession's performance in relation to service delivery in AR in the following way:

> *I had never had anything to do with the hospital system before this ... and I am absolutely flabbergasted that it operates so... Having been in the hospitality industry for so long and being so tuned into other people and what their needs are, I am amazed that the medical profession is not tuned into who people are. (Jane)*

That anyone seeking the services of a health professional is treated in this way is disturbing but the nature of human *reproductive* procedures should result in a stronger imperative for ethical practice and should command genuine respect for service users and not a violation of basic human rights to privacy and dignity. After all, as one woman said 'having a baby is a magical thing' (Clarissa) and service users are 'not just there for an appointment' (Lindi) and need to be 'nurtured' (Leonie).

Clinic facilities

Participants indicated that the most important aspect impacting on their experiences of service use is the nature of interactions with clinic staff, the practical aspects of service use, including the clinic's physical setting and features, also impacted on overall service quality. Several of the regional clinics used by participants were not stand-alone, specialised or purpose-built AR facilities and many operate by sharing facilities with other local health service providers such as day procedure facilities, general medical consulting rooms and private hospitals. This was especially so for satellite clinics but some of the primary clinics also shared facilities in this way as well. Some primary clinics were co-located with general gynaecology practices as well and many women were aware of the full range of issues presented by clients of the practice as well as the range of procedures performed by medical practitioners. Many women found it somewhat uncomfortable for example, that induced abortions were also carried out at their clinic and while this discomfort did not necessarily reflect their moral views about termination of pregnancy, the irony of some women being there to try to achieve pregnancy while others were there to discontinue pregnancy, did not escape participants. In fact at one clinic, it was almost impossible for this dual purpose to be ignored due to the regular presence of anti abortion protesters outside the clinic. Many participants had to dodge a picket line of these protesters as they entered the clinic:

> *While I don't agree with abortion, I am not going to go down there and picket the place that helped me get my child. (Toni)*

> *I remember going to the clinic one day and they had protesters out the front and I've never come across that before... And I thought I beg your pardon but we are trying to have a baby. And we got in the car and one of them banged with a big board that they had and they were looking at me and I'm thinking – they don't even know why I'm here... Apparently they're against IVF anyway as well... That really ticked me off...I was pretty shocked...Apparently they go down there quite often... They're not allowed on the premises. (Tina)*

> *Apparently they are there every single week... They would yell out 'think about what you are doing'... That was very sad and I was very annoyed when I left. (Amber)*

We were there one day and they had this big cross with a foetus on it... I was very much aware of the need for good termination services and I know it's a horrible irony that our doctor does both... I believe there is a place for it but it was horrible seeing these mostly old men... They seemed to feel that they had a right to go there and it was horrible on lots of levels and it shouldn't have been something we were exposed to, not nice at all. (Sarah)

Sarah went on to describe how after her experience of the protesters, that she and her doctor had the 'best appointment ever' because her doctor, uncharacteristically, engaged in 'a good chat' about the protesters with her. Perhaps the presence of protesters on that day had not only disrupted the usual routines of the clinic, but also the doctor's usual 'business-like' approach and he could engage with Sarah on a more personal and contextualised level. And while there are no easy solutions to this situation and if protesters confine themselves to public areas, there is quite possibly little that can be done to protect service users, regardless of the nature of their service use, from this sort of behaviour. It highlights a need for the clinic to provide adequate support to all clients who have been harassed or confronted in this way. None of the participants who had been exposed to protesters had been offered any systematic follow-up counselling or other support, except for Sarah's 'good chat' with her doctor.

Overall, the most positive assessments of clinic facilities came from women who had used primary clinics and the most dissatisfaction came from those who had used satellite clinics. Many of these women complained about inadequate waiting areas and inappropriate 'treatment' rooms in particular at satellite clinics. Reception and waiting areas were often shared with all general clients of the health service and in some smaller communities; this was problematic for those wishing to maintain privacy about their use of reproductive technology.

You do people-watch, you look around and wonder why they are there, who else is on IVF. You see the same faces every now and then... Nobody meets your eye but it is fairly obvious why they are there... Some people might say yes, we are doing IVF but they still don't really want to talk about it too much and I think that is their prerogative. (Clarissa)

You would go to pathology [the only pathology service in town]... and there would be four or five other women there and you would be all looking at each other out of the corner of your eye, thinking 'I wonder if'... Then you would leave there and have your ultrasound and the same group of people would be there and it was just too much of a coincidence. (Elle)

A strong theme emerging from participants' comments is the feeling of being 'rushed through' by satellite clinics, with Felicity's comment (below) being typical of several other satellite clinic users' comments. Kylie's comment also comes from the context of having used a satellite clinic and she further illustrates the lack of respect, attention and privacy afforded to women at that clinic:

You have just had this embryo put inside you and you want to sit still and make sure it doesn't move anywhere but I thought they were quite pushy because there wasn't enough room and I kind of had to go... I complained about that as well... it was just the IVF that day but because it was all done bang, bang, bang, bang, bang, there just wasn't room for everyone. (Felicity)

We were in our gowns, sitting there, you know, it is quite cold in there and we were all saying 'gosh it's cold in here' and we were not offered a warm blanket ... We were nervous, we didn't know what to expect really. You could feel tension with all the couples sitting in there and you would be wheeled in, in the wheelchair and you could see some of the ladies crying and some not... I don't know you just expect when you are wheeled in maybe a hand on your shoulder saying 'it is OK, this is what we're going to do'. I didn't feel it was explained very well... We had to sit for half an hour and then go and get changed and off we went...I was pretty much an emotional mess and my husband was trying to calm me down. I was in a lot of pain and not even the coordinator or the nurse came to see me, they could see I wasn't joking. They just stuck a pad on the wheelchair – 'sit down on that, off you go'. I just felt that, you know, and those gowns are open all the way down the back...(Kylie)

Both Kylie's and Felicity's comments come from relatively recent experiences of AR at the same satellite clinic (post 2000) and yet they reflect some of the earlier comments and first wave feminist criticisms about AR in its pioneering days (e.g. Klein 1989 a & b). While Jan, who used AR in these early days, described staff as 'professional' but said that service use for her in the early 1980s felt 'like an assembly line'. Amber, also referring to the same satellite clinic used by Kylie and Felicity, spoke about the lack of privacy post-procedure and how at a time when many would feel a heightened need for privacy, that it was not an option:

In the waiting room there was no separate area at all... straight away everyone knows because of the way they put you back in a recliner and sit you back with your legs elevated and because the coordinator is with you, it is a dead give-away each time...I think for most people it is a fairly intense, private thing. (Amber)

Amber also commented on the use of inappropriate rooms for procedures. She said that the room used for her embryo transfer was very large and that she had found this 'disconcerting' (Amber). Sarah spoke about her (primary) clinic's use of a 'through-way' space being used for some procedures and of the consequent lack of privacy for clients. Amber who had used two different clinics, one in a metropolitan location and one in a regional location, also spoke of the lack of privacy at the metropolitan clinic and of having...

...only a curtain that shielded you from the next person so when the doctor came to give you feedback about eggs or whatever, you heard the lot. At least

here [regional location] that was completely private and confidential. I was amazed that you could do that to women. (Amber)

Elle specifically commented on how she thinks that the satellite clinic model impacts on the lived experience of AR:

I would prefer the clinic to be here full time because then I don't think it would be as busy. You wouldn't have to run into people everywhere you go for your tests and realise that they are here for the same reason and you don't have to synchronise your cycle... like part of a herd of cattle, it didn't feel personal. (Elle)

The more positive experiences were typically marked by a less pressured, less mechanised and more comfortable overall experience where clients could sit for as long as they needed to after a procedure, 'ideally with a cup of tea and your feet up with a warm blanket' (Clarissa). Others appreciated the extra non-clinical touches made by some services such as aromatherapy oils, dimmed lighting, massage and background music , which according to Anne was 'much more relaxing'.

Other aspects of assisted reproduction

The issue of control, specifically lack of control, was raised by almost 90% of participants. Various forms and degrees of loss of control as the result of involuntary childlessness and use of AR were described including loss of bodily control, loss of control of life choices, loss of control over AR procedures and uncertainty about outcomes. For several participants, a way to regain some sense of control was to pursue alternative health options outside the traditional biomedical sphere. Some women consulted herbalists, some used acupuncture, some used hypnosis, or lunar cycles, while others used the services of a naturopath, or iridologist, or aroma therapist and one had consulted a witch and one a Chinese herbalist.

I did everything under the sun. Some of it good, some of it a bit outlandish, but I kept saying 'I can do it, I can do it'. (Jane)

The determination is so great that anything is worth a try. (Sarah)

I suppose I was just trying to reduce the stress levels and get my life back... You are actually physically doing something to make a difference, getting control back over my life and my body and my family I suppose. (Sharon)

Several participants spoke about how they tried to improve their general health as a possible way to encourage success with AR and to overcome involuntary childlessness – 'diet and environmental things' (Leonie). Some felt that the medical profession had neglected to assess basic health and lifestyle factors and that alternative health resources were likewise ignored by most medical practitioners. This echoes concerns

raised in the literature review (e.g. Field 2008; Leger 2007) that broader health issues are not adequately addressed before referral for assisted conception:

> *It's right across the medical profession – they rarely bring in issues like naturopaths and alternatives... I think they need to be a bit more in tune with alternatives. (Carmen)*

> *I was very aware that my general health had a lot to do with it. (Jane)*

> *... To get myself physically fit and emotionally strong. I was very fit. I went out and joined a gym and that helped a lot... I sought counselling for a couple of sessions so mentally I was right. I just had to get my body physically right... get as healthy as possible... Surely that is going to help. (Sue)*

Jane also spoke of being surprised that there was not more assessment of psychosocial and health factors such as relationships, employment and nutrition:

> *I thought – they just don't know people... At no time did anyone ask how our marriage was ... nowhere along the line did they check that... no-one asks what is going on in their life, they never asked me what I did... So that surprised me when they said 'just go back and do what you normally do' when they never asked what I normally do! ... The medical world has always kept itself aloof from what is going on in heads and what people eat... Nature is bigger than all of us. (Jane)*

In summary, the participants' comments relating to clinical service provision indicate that satisfactory service provision depends on a combination of factors with the main factors being clinical competence and professional, respectful, ethical behaviour from all clinic staff. Ideally a clinic's facilities should offer comfortable, private spaces for women and their partners to use and procedures should not be delivered in a rushed, mechanistic, 'assembly line' manner. It seems that while some compromises can be made by women in terms of physical comfort and even privacy, that the prime factor in positive service delivery is competent clinical care delivered by people respectful of clients as individuals and respectful and mindful of the purpose and meaning of the services being delivered.

In addition to competent, caring clinical service delivery, participants also universally indicated a range of psychosocial support needs arising from their experiences of involuntary childlessness and use of AR. The following chapter will focus on these support needs as well as on access to and experiences of formal support such as counselling, groups and online support in addition to informal support.

Chapter 11 - Support needs and sources of support

The previous chapter detailed how some procedures administered at reproductive technology clinics led to participants feeling depersonalised and disrespected as active subjects in their own right. The literature establishes the importance of service users' access to ongoing, comprehensive psychosocial support measures as a central requirement for respectful, client-centred, quality service delivery and to a deontological approach to assisted conception (e.g. Haase 2007; Emery et. al 2003; Hammer-Burns 1999). All participants indicated that along with their biophysical needs, there were also psychosocial support needs arising from their experiences of involuntary childlessness and their use of reproductive technology. Moreover many comments made by participants about their support needs indicate that the biomedical approach to reproduction does indeed dominate most service providers' approach to assisted conception. As a consequence, there is too often a lack of attention to psychosocial needs of service users by most, though not by all, clinics used by participants. The following quotation from Jacquie illustrates this point:

> *Everyone's concentrating on the science of it all, on the medical aspect of it all whereas support needs probably just get overlooked. (Jacquie)*

The following discussion specifically focuses on the range of participants' support needs in addition to sources of support, including informal support from family and friends, as well as formal support and experiences of counselling, groups and other support mechanisms.

Informal support

Almost two-thirds of all participants accessed some sort of formal support services at some stage during their AR experience. In relation to sources of informal support, two-thirds of participants said that their partner was their main source of support and slightly fewer said that family and/or friends were highly supportive throughout AR. Factors indicating the supportiveness of partners included responsiveness to varying needs throughout AR and respect for self-determination:

> *I feel that a supportive husband is the best thing you could have. Mine was just magnificent through the whole thing... He was happy to do whatever I wanted to do and when I wanted to do it and he was just fantastic. And that really, really helps. If you've got a husband that's not so keen on it I'd say that would make it that bit harder. (Carmen)*

Only four participants said they fortunately knew other women using assisted conception clinics and spoke of this type of support in very positive terms. Ivy, for example, said that her connection with another service user was 'like we were in a little club together'. Jan spoke about the camaraderie of the clinic waiting room when she was a service user in the 1980s; she said they would compare experiences – 'oh

yeah we all compared notes!' Jacquie also mentioned the clinic waiting room but in a less positive way in terms of support:

> *I knew that an acquaintance of mine was on IVF and she probably knew that I was but we never actually said anything to each other. And you know we'd actually see each other in the waiting room and say 'oh hi' and we never actually talked about it... Yeah it's quite funny that we've never sort of acknowledged it. (Jacquie)*

Jacquie's comment also highlights another aspect of service use that is of particular relevance to women living in smaller regional communities – privacy. As discussed in the previous chapter and in the literature (Cheers 1998) there is often a lack of anonymity and privacy in such communities – 'everybody knows everybody else's business' (Leonie). This can have mixed effects as the following quotations illustrate:

> *Oh all the people of the whole town ... I mean this is a little town, news soon spreads. Yeah I mean everybody was wonderful, everybody. (Jan)*

> *Another interesting thing about our town is that the IVF counsellor also works [at another local organisation] so I have actually ended up meeting with her through my professional life as well. So that is an interesting thing in that you don't have anonymity that you would have in a larger centre...although in some ways it works in your favour. (Amber)*

> *Being in a small town you can't be anonymous. (Sarah)*

As well as support from partners and other women with experience of involuntary childlessness, close family and friends were understandably also sources of informal support for the majority of participants. However, a strong theme emerging from the research interviews is how the experience of involuntary childlessness can sometimes erode the usual sources of support for participants. Some felt unable to continue close social contact with certain friends and family especially those who were having children with apparent ease and some felt that they could not 'burden' their friends and relatives with their distress over their fertility issues. Some women said that they felt too embarrassed about their fertility problems and were reluctant to disclose this to significant others while others actively avoided contact with some people at certain times as a protective measure, for example:

> *A lot of people are pretty private about it [infertility]...some people might be embarrassed about it. (Tina)*

> *A really good friend ... had two children ... she was very supportive of me but I found it very difficult at times to be with her with the kids because it was just too in my face and at other times it was great to be able to go around there... I knew when I could see her and I know which days of the month and which times I simply have to avoid her. And she was good about that, you know, if I didn't*

come around, there was a good reason and I would catch up with her in a week or two when I was feeling better. (Sharon)

Sharon's comment illustrates how the nature of involuntary childlessness can come to dictate many other aspects of life and how it can become 'all-consuming' (Sue). Some women also spoke of the erosion of their usual supports from the perspective of their friends and family; some felt that their family and friends might be 'sick to death of hearing about' infertility and that they were therefore reluctant to 'put pressure on them (Sue) and others noted that some significant others felt awkward 'because they were having babies ...and I wasn't' (Jacquie). Kerrianne commented that her support network was there for a wide range of reasons and she was conscious of not 'using up all their support just in the IVF area'. Carmen said that some people from whom she expected support turned out to be 'the least supportive' and she described this as 'a big shock' but also acknowledged the mutual challenges for all involved:

I think they felt a bit shut out by us at the same time... people do a bit. You feel isolated and think you're the only one and that you're on your own. And if they don't understand they tend to step back a little bit. (Carmen)

Six women commented specifically on how the duration of the experience of involuntary childlessness altered the nature of their initial support systems and this then exacerbated the longer term isolation they experienced, with the range of sources of active support generally decreasing over time:

For the first couple of cycles people would ring ... they would lose track ... But after a while that stopped because they figured out that she will tell us if there is any good news and they would wait for me to tell them if there was bad news. I think really each time I had a failure I would withdraw more, I would talk less about it. (Sarah)

At first we told all our family and friends and when I miscarried it was really hard because they all knew... The second time around we only told Mum and the third time around... no-one else knew. (Sue)

For the majority of participants it was important to be selective not only about *who* they told but also *what* they told their informal support network about their situation and outcomes of AR procedures – 'I just picked and chose who knew how much' (Sharon) and 'you only tell them what you want them to know' (Anne). This selectivity in support people was usually described as an attempt to control the frequency and quality of contact from others about AR cycles. Several women wanted to avoid receiving numerous telephone calls at the time of waiting for pregnancy test results. As in previous chapters, this two week waiting time was consistently described as the worst time of all by almost all participants. For some the duration of AR use had reduced their willingness to discuss it; some felt they had become 'just sick of thinking about it' as AR use wore on (Lindi). A few women described using 'special codes' for

163

telephone calls so that calls could be screened at crucial times of the AR cycle, for example:

> *Sometimes after we found out it didn't work I didn't want to talk to anyone. My Mum would have a special code...so I'd know it was her...I wouldn't answer the phone to anyone else... I was quite happy to tell people once I'd gotten over it ... but I knew once I got on the phone and said that it didn't work I'd go boo hoo hoo and I hate that. (Jenny)*

Five participants described that there was a trade-off in selective disclosure in that limiting the number of people who know also places corresponding limits on the number of potential support people. When interacting with those outside of the selected support group, interactions can become challenging because certain key information has to be omitted from conversations and in times of upset, other reasons might need to be found to explain the situation. While most participants had told at least their immediate family and close friends about using AR, a small proportion had chosen not to tell anyone else at all:

> *My husband likes to keep this sort of thing to ourselves, so I think we just sort of leaned on each other all the time... We just stuck to ourselves. It could have been easier I think... But each cycle we went through we got over quite quickly, held each other up, tore each other down at times. (Phoebe)*

> *I didn't have to deal with anyone else's emotions, only my own, I found that easier. (Amber)*

Over two-thirds of participants specifically discussed how their male partner's needs for psychosocial support through AR often went unrecognised. Seventeen of the nineteen women spoke of the dual impacts on men of being a key support person for them while also experiencing their own distress as involuntarily childless males.

> *He had his own grief as well but I just wanted him to support me so that was awfully hard for him. (Sarah)*

Eight women spoke about the impact of traditional masculine expectations on their partners, particularly in relation to their partners feeling unable to legitimately express emotion.

> *Men don't get as emotionally involved, well they don't show how emotionally involved they are, probably because it's not happening to their bodies. He would be disappointed but he would never show it, he would just say 'let's get on with it, let's be positive' but I would need to have a cry – I need a cry. I need to get to the bottom of this well and then I will climb back out again, I can't always be positive. They deal with it so differently on the whole. (Sharon)*

> *Colin doesn't talk about it much. If someone says something about IVF he is quite happy to say we are doing it but he doesn't volunteer any information and*

I often think he is not interested but it is only because he is not physically doing IVF that he forgets… His appearance is of disinterest but I think he just forgets we are doing this together. He doesn't like to talk about it, he does what he has to do and that's it. (Clarissa)

I guess it affected him but he didn't want anyone else to know how it affected him. So he got a bit quiet usually after things didn't go right, he'd have a bit of a sook, a cry, and then get back to his work, he's very dedicated to his work. (Jenny)

I think it's a manly thing as well and having to get tested to make sure, you know, that he is good enough. He couldn't stand a low sperm count, he would be devastated. (Elle)

I think in our society men really like to think they can produce the goods. (Jacquie)

Comments from seven women also suggested that men are perceived to use a more restricted range of coping strategies in comparison to women, as suggested by Slade et al. (2007) and Roach-Anleu (1999).

I think that he thinks if he doesn't talk about it, it might just go away, perhaps. Perhaps he thought that to confront infertility that he would be confronting a bit of his manhood, maybe. He didn't discuss a hell of a lot of it, you know… you don't talk about these sorts of things, you know? (Sue)

It was probably harder for Lewis because … he really didn't have access to anyone except me. (Leonie)

If something's bothering him he just goes off with his mates to the pub, has a few drinks with his mates, that's it. (Jan)

Four participants expressed concern for men's collective welfare and identified a need for more research into men's wellbeing as well as a need for more support specifically for men:

You could see the husbands in the waiting room; the husbands were so nervous. You know it was really awful. My husband was nervous; he didn't know what he was letting himself in for. He'd never seen me have a medical examination or anything like that before.(Kylie)

They need to consider men a lot more in this whole thing – the rollercoaster for men. You need to be aware of the male side of things and the support that men need. My husband said that he didn't think the support was there for him. (Judith)

It would be interesting to interview men. I don't think there would be too many that would be willing to talk but it would be interesting. (Leonie)

Have you spoken to any men? It would be interesting to get it from their point of view because I think that men don't feel so free and easy to talk to their mates about these things. (Phoebe)

Formal support - counselling

While participants made it clear that having some degree of reliable informal support was important, 24 participants also identified the need to have access to formal support mechanisms. As Kerrianne (below) said there can be a reluctance to fully disclose one's psychosocial situation in detail and depth to family and friends for fear of overloading them.

Counselling gives you that concrete support outside the family network. I find that IVF really drains your family and friends ... I mean you're consumed by it and that's a day-to-day thing for you and you don't want it to become a day-to-day thing for them. So you're limited on how much you say and it affects your honesty as well like 'how are you going?' – 'Oh yeah I'm doing really well' when really you're not...It's a lot of superficial stuff. (Kerrianne)

The need for formal counselling and support is well-recognised in the literature and in the accreditation guidelines for Australian service providers. Based on information from FSA accredited AR clinics' websites (FSA 2009) sources of psychosocial support at AR clinics in Australia does vary in terms of counsellors' qualifications. Clinics generally acknowledge the importance of psychosocial supports and they provide access to counselling to clients, in many instances clinics (45%) don't provide any detail about the specific professional qualifications of their counselling staff. Approximately one-quarter of sites indicate that their counsellors are qualified in either psychology or social work and that their counsellors have ANZICA membership. Eighteen percent of clinics list psychology-qualified counsellors only and 3% list social work-only qualified counsellors. Eight percent of clinics had no accessible website information at all about the nature of counselling support. There was considerable variation in the cost of counselling with some clinics including at least one session with a counsellor as part of the global fee paid by clients while at other clinics, counselling was an additional cost; a few clinics did not advertise detailed information about the cost of counselling. There was also a lack of information specifically in relation to regional satellite clinics' provision of psychosocial support. While parent or primary clinics indicated that counselling was available at the primary clinic, access for satellite clinic users was not usually specified. Most clinics indicated that psychosocial support was offered to individuals, couples and groups and many sites especially emphasised the importance of counselling for those using donors.

Fifty eight percent of participants accessed some type of formal support, typically a clinic-appointed counsellor. Significantly, 28% of all participants had wanted to see a counsellor but did not and 14% did not see a counsellor because they chose not to.

The majority of women who had accessed counselling mostly used the clinic's counsellor (almost 90%) although some had accessed a counsellor independent of their clinic (just over 10%). A few had the opportunity of attending client groups organised by their clinic and most participants had accessed online communications sites (e.g. blogs and chat rooms).

Thus the option to access professional counselling, support and information groups is needed to ensure that each service user has an adequate range of support options available to deal with the various impacts and 'complicated grief' (Lechner et.al 2007, p.288) of involuntary childlessness and assisted conception. For Felicity however even though there was an identified clinic support person with whom she had regular contact, there was also the perception that disclosure had to be limited due to the clinic's resource limitations:

> [*The nurse coordinator*] *was really nice but she was extremely busy, so when she would ring me every day and say 'how are you?' I always felt I had to say 'fine' because she didn't have the time to talk to me and I know that there was something like thirty three other people doing it when I did it and I thought she has got to ring thirty three people and everyone of them want to tell her their problems, she wouldn't get anything else done. (Felicity)*

As expected there was a range of views about the usefulness of counselling from 'she was bloody useless' (Sharon) to 'counselling was definitely useful' (Tina). However of the thirteen comments specifically about the usefulness of counselling, only two were unequivocally positive, three were neutral and eight were clearly negative about the usefulness of counselling.

> *The counselling we had at [metropolitan clinic] was not very good...It was really based on negatives and she did all the talking and directed questions at me... There was no counselling whatsoever at [regional] clinic. (Marion)*

> *I used to call them the perfumed steamrollers; they were lovely but they would just roll right over the top of you and while you were just sitting there saying we need help with this and that they would be saying 'yes' ever-so-nicely but just rolling right over the top of you. You would walk out of there thinking well I didn't get anything out of that at all. (Lindi)*

> *The counselling clarifies your perspective on everything and you can see clearly again. (Sue)*

> *We had an interview with the psychologist just to make sure we could cope with the emotional rollercoaster. (Clarissa)*

An important factor emerging from this research is the variation in the level of awareness amongst participants about the purposes and availability of counselling and/or support groups at their clinic. For most, the purpose of counselling and other

formal supports was seen as, ideally, to offer neutral, 'safe' emotional and practical support outside of one's intimate network, as well as a venue for unrestricted disclosure of feelings about assisted conception. As most of the participants accessed AR services in the state of New South Wales, where counselling was not a legislated, mandatory requirement at the time of their service use or at the time of interview, many women reported confusion over whether counselling was compulsory or not with many being under the impression they 'had to' attend counselling at least once to be eligible to use AR services. This lack of clarity from the outset about the nature of counselling is at odds with principles of informed consent, client self-determination and autonomy. If the counselling relationship proceeds on the basis of confusion and misinformation it is surely questionable in terms of standards of ethical, professional practice (AASW 2003; AASW 1999).

> *You have to have the counselling session, I don't know whether it is law in New South Wales or not but we did that. (Felicity)*

> *We had to see her it's part of it; I don't think you've got a choice. She was just there... They didn't tell you what the counsellor was there for I just sort of assumed that she'd be there to say 'yeah you're ready to go on IVF' but I don't think that's what she was really there for... But yeah I thought she'd be there saying 'oh you're not going to be a good parent'... They don't sort of explain what the counselling is there for, they just say she is going to be there for your next appointment...I think they should explain it a bit better to say she's not there to judge you...She was a nice lady but I didn't know what her purpose was'. (Josie)*

> *We had to go and see a counsellor and it was just nerve wracking...I felt like it was going to be her say whether we were able to continue... and it felt like an interview if you know what I mean. I kept thinking 'say the right thing, say the right thing' instead of being able to discuss how I really felt... It wasn't comfortable and relaxed...you felt like you had to pass. That is how it felt – pressure... You don't want her to fail you...She was a really nice lady, she would have been a nice person to talk to and say look I'm just not sure how I'm going to cope but you just go no, I think I'll be fine... They have got to be the right answers that is how it felt...I don't think it was helpful...She would have her little clipboard and be writing down things and it was almost like an exam, it was horrible in that situation I was just keeping myself from really talking to her. (Elle)*

Clarissa commented that 'it didn't occur to me to say no' to counselling and she identified the purpose as 'to make sure we were fairly well adjusted'. Amber identified a similar purpose for the counselling session and felt that her desire for parenthood was being assessed as well as how realistic her expectations about success were: 'to suss out how desperately we wanted children and the fact that we may not get them through IVF'. Amber also said that although the counsellor was 'very pleasant and

positive' that counselling did not offer her anything she 'hadn't already figured out'. These comments echo Klein's (1989b) findings about clients' perceptions of counselling as dual purpose as well as her findings about the power dynamics at play; in particular service users' views of the counsellor's perceived power as gate-keeper for reproductive services. The participants' comments also indicate the mostly negative impact of these perceptions on the counselling relationship with most participants indicating that they presented an overly positive account of their situations in order to maintain access to AR.

In addition to these contextual challenges to effective engagement between counsellor and client, some participants described quite a procedural view of counselling, almost akin to an inoculation approach to psychosocial counselling and support, in that having one session seemed to be seen as sufficient to 'tick the box' in terms of assessment and support. This seemed especially so for women who had used more than one clinic. For example, Leonie said that because she had counselling at an interstate clinic prior to using her local one, they did not see the need for further contact from the counsellor at the new clinic 'because we had already gone through that'. Sarah commented that there was an assumption, based on her own professional qualifications in allied health that she somehow therefore did not need to see a counsellor. She also indicated some confusion about whether or not counselling was mandatory, saying that her clinic located in New South Wales 'waived' her counselling session. This procedural view of the counselling process is at odds with much of the literature in that most recommend ongoing psychosocial support at all stages of the AR process due to the wide range of impacts of involuntary childlessness and assisted conception on the life course, the frequency of failed AR cycles, and the need for service users to be actively and holistically engaged during service-use (e.g. Campagne 2006; Peddie et.al 2005; Throsby 2004; Emery et.al 2003; Dominelli 2002).

In terms of counsellor expertise, one participant, who used a clinic that at the time of her service use outsourced counselling from local private practitioners, described her experience as 'uncomfortable' because:

> *I ended up seeing someone who was fairly new and hadn't seen any other IVF clients before and... I found she started to psychoanalyse my childhood and I couldn't understand what that had to do with the current situation and IVF...I reported back to them what she'd actually done and they ended up finding someone else. (Phoebe)*

Another participant chose to use a private practitioner unconnected with her clinic and she indicates that she felt that flexibility and independence in this regard met her needs at the time more effectively than the clinic counsellor could. Sue's comments (below) reflect the importance of neutrality in the counselling relationship (as in Ewing 1999):

I sought [counselling] independently, I didn't go through the IVF clinic... I went through an independent one just to perhaps disassociate myself from the clinic...Not that I wouldn't use the clinic's counsellor at all, but that is just the way I went, that is just what I needed at the time. (Sue)

For three participants, counselling was wanted but none was made accessible to them; Jacquie said that 'counselling was not offered' and that if the clinic had a counsellor that she 'never met them' during her service use. Marion did not think that her regional clinic had any qualified counsellors on staff and that she was getting a 'biased view' from the nurses at the clinic. Kylie was especially disappointed that her request to see a counsellor was not met and that counselling support was not more integrated into her experience of AR:

We wanted to do some counselling...We didn't hear from them once...And then they found out that yes, we were pregnant, then the counsellor rang and they said 'how was the procedure?' I said look it is all over and done with, we have got what we wanted, we are pregnant, we can take it from here now. So that was a bit disappointing, because I really needed it because I was really emotional the whole time...I just found that support system and maybe the promise that was written in the booklet, the way it was written – 'we are here to support you' and it was... we didn't feel it. (Kylie)

Some participants chose not to see a counsellor, some because they felt they 'didn't need a counsellor' (Lily), some because they did not 'believe in counselling' (Ivy), some because telephone counselling was all that was offered – 'they gave us toll-free numbers that you could ring and talk to but I didn't feel like I needed that' (Belinda) and some because their informal support systems were considered adequate; for example Judith who said 'I didn't need to... Look we've got our parish priest and we've got ourselves'.

Formal support - Groups

Approximately 15% of participants had actually attended a support and/or an information group during service use, with one participant having been instrumental in establishing a self-help group at her local regional clinic. According to participants, the benefits of group attendance based either on their actual experience of attending a group or on the perceived benefits of group attendance, included:

- *Shared experience* - 'getting support from someone who understands IVF...to validate that how they were feeling was normal' (Sharon) and 'People going through it are the best ones to talk to... no, I am not abnormal' (Sue), 'seeing other people who it's not working for' (Kerrianne), 'we were kindred spirits' (Carmen), 'You realise you're not the only one' (Amber).
- *Inspiration* - 'others getting pregnant and giving you hope...If she can do it, I can do it' (Sharon), 'To speak with people who've had success after a long time

so that you can see light at the end of the tunnel' (Phoebe), 'people look for inspiration...My inspiration was a 42 year old woman who then got pregnant naturally' (Marion).

- *Atmosphere* – 'It was very informal...I looked forward to it because I could ask them questions that sometime I might not have wanted to ask the nurse' (Anne).

- *Practical help* – 'developing resources like a library because the books are so expensive ... And organising discount accommodation at a motel near the day surgery...It was really beneficial because of the practical stuff no-one else seemed to be able to offer' (Kerrianne).

By far the most common benefit of group attendance was the shared experienced element of group participation. Most women said that there was no substitute for the lived experience of involuntary childlessness and use of assisted conception services. Participants also made a clear distinction between the sort of connection and support from other women with shared experiences and the sort of support they received or thought they might gain from a counsellor. This emphasises the value of experiential knowledge in the context of AR.

Almost one-third of participants said they would like to have attended a group but they had not had the opportunity to do so. The most frequent reasons were that the local clinic did not offer a group and/or that they were unaware of whether there were other groups operating in their local community. Most of these women also said that group attendance would offer them contact with other women in situations similar to their own; so the perceived benefits of shared experience were important for these women too. For women without local family support, the prospect of a support group was additionally attractive as was the desire to make open connections with other women in a safe atmosphere. Some were much more interested on information-based groups than on support-based, self-help groups:

> *Something where they could bring out a scientist and they have a talk about a procedure so that we are getting up-to-date information...rather than going in there and whinging, blah, blah, blah 'we have had such a terrible time'. We need something a little more constructive rather than a cup of tea and a whinge about IVF. (Clarissa)*

Clarissa's comment illustrates the need for groups to be effectively facilitated by a professional helper with an appropriate knowledge of group processes to ensure, amongst other things, that a negative atmosphere does not come to dominate the group and to ensure that the benefits of shared experience are not overshadowed by the loss of hope and negativity that could accompany shared experiences such as failed AR cycles. The complex task of facilitating such a group would require the group

171

worker amongst other things, to monitor levels of heterogeneity and homogeneity appropriately in group composition over time.

Some women were not enthusiastic about groups at all (approximately 11%) and even where the opportunity to attend a group was offered, chose not to attend. Lily for example, felt that she got adequate support from family and friends and Ivy felt that she was too self-focused at the time of service use and that she did not want to 'come home with other people's problems when you have enough of your own'. Some other potential drawbacks of groups based either on experience of groups or on perceived drawbacks, include:

- *Lack of group cohesion* – 'It wasn't a group that gelled very well...We felt like here we are a bunch of losers or something...it just wasn't a support for us' (Sarah).
- *Group facilitation* – 'You need a professional facilitator to manage conflict and times when some members are having success and others aren't' (Sharon).
- *Resources* – 'The group was becoming smaller and smaller and then that becomes not financially viable either, people's circumstances changed' (Kerrianne).
- *Negativity* – 'We were down to about three of us...The numbers were really low' (Kerrianne), 'some people use them as a crutch and they actually make that situation worse for them' (Clarissa), 'people that have success go about their own way leaving this group of bitter people' (Jane).
- *Privacy* – 'A lot of people have trouble with privacy and... They're not willing to go to a group, whereas if they just duck into their clinic it can still be relatively private' (Kerrianne), 'do I want to walk in the door and meet the next door neighbour?' (Vikki).

These comments underline the need for client groups to be run by an appropriately qualified professional facilitator with adequate resources and support from the service provider.

Other sources of support

Almost all participants used internet resources for support and information. A minority actively contributed to chat rooms and blogs; the majority limited their use to watching and monitoring sites but did not post any contributions. Generally the online environment was spoken of in very positive terms and the opportunity to connect with other women using reproductive technology from around the world was described by most as beneficial. The online diaries of AR users were mentioned by several participants as offering realistic accounts from other women about the range of experiences of AR:

172

A couple of IVF patients had diaries which is useful. It can be demoralising because you can feel their pain and their heartbreak, having been through it you can relate to it. So yeah at the time I did find it useful and you get a better idea of what to expect. (Judith)

There were a few testimonials and there was actually one person's diary and their day-to-day experience, which was great...It was actually a real person, it is not medical, it is not clinical. (Elle)

I would look at a website as opposed to chatting to people online. I would email someone with a question or something...Being able to email someone with a question is really helpful because it is not so confrontational and it is personal and takes away those barriers sometimes...Anything to help ascertain what the experience is like... I think it is an important step in the process, rather than going on what you read and what you get told by the coordinator, to experience... I think to hear about someone else's experiences would be the link between those two steps, I really think that, yeah. (Jane)

Jane's comment highlights the value placed on experiential knowledge and the need for a range of information and support for services users and for there to be a balance in technical and experiential types of support and information. One participant felt that the online information was not balanced and another that websites have limitations in terms of support but that they could be useful for information, especially for women living in isolated areas with limited access to direct contact with service providers:

I found solace in the internet, not chat rooms but getting into websites devoted to IVF. They're mostly American ... You do generally get positive outcomes, you don't very often hear about the ones that don't succeed. (Marion)

I think I would use it only for information; I still think there's a lot to be said for face-to-face contact with people. I think it's a little bit more personal that way, so for me face-to-face is more valuable than having something online. But if you're ... living in an isolated town somewhere then the internet is good for the technical side of it but not I think for the support side of it...or even a phone line, a help line that you can actually talk to someone who has been through it. (Phoebe)

In terms of telephone support, one participant had used a telephone helpline and did not find the experience helpful. The following comment from Lindi also highlights the need for clinics to ensure that the information they distribute is reliable and that referral services are of a suitable professional, ethical standard:

I rang a lady on a support line and I actually found her very difficult... I don't know, she was very hostile and I was thinking hang on, I've rung you for help, not for you to lecture me... I got this lecture on 'don't be irresponsible, are you aware of what you're creating?'... I got the number through the clinic or

through some pamphlet or something they had given me. We had no idea where to go or what to do. (Lindi)

For many participants, having hobbies, paid employment, volunteer work, and the like were sources of distraction and support through the AR experience. For example, Judith used yoga, religious faith and exercise as additional means of informal support as well as 'just trying to keep busy' and these strategies, she said, were helpful to her.

In summary, this chapter has presented and discussed participants' comments about support. The comments reinforce the literature on support in this context as they emphasise the need for a range of ongoing support mechanisms to be accessible to services users. Informal support is clearly the most foundational support structure for service users at the interpersonal level but the importance of the service provider's approach to the provision of formal support is clear. Clinics need to offer reliable, professional and purposeful psychosocial support for clients, including men, at all stages of service use. The provision of one-off procedural or crisis-driven counselling appears to be inadequate in meeting the requirements of most participants. The need for service providers to recognise that assisted conception involves more than purely technical, biomedical procedures is vital if good quality total service delivery and positive service-user experiences are the aim. The limitations of a predominantly biomedical approach to service provision and psychosocial support are clear.

What else did participants say about their experience of AR, the quality service provision and what were the outcomes of service use? In addition to questions about support needs, participants were given the opportunity to identify what they would like to have said to their service providers about the positive and negative aspects of service use. Participants were also asked whether they had any advice that they would like to give to other women contemplating using reproductive technology. These comments and recommendations based on this experiential knowledge are explored in next chapter along with a summary of the outcomes of service use.

Chapter 12 - Outcomes of assisted reproduction and participants' recommendations

The preceding chapters have presented participants' experiences of and views on involuntary childlessness and their decision to try assisted conception, their experiences of and views on many aspects of AR service use, the various impacts of AR as well as their support needs. The stories told thus far have established that while assisted reproduction is a valued option for those wishing to redress involuntary childlessness, too many women found the AR experience unnecessarily medicalised and disrespectful. The inadequacies of service provision are primarily attributable to an over-reliance on the biomedical approach to service delivery and to the devaluing of (if not invisibility of) the experiential, situated knowledge of women as active subjects.

This chapter focuses on the outcomes of AR for the participants, reflections on their experiences as well as their recommendations to clinics and potential service users about assisted conception.

Outcomes of service use

Ninety three percent of the women who participated in this research had given birth to at least one child via either natural conception or via AR and only 7% (2 women) were childless at the time of interview. One of these women had experienced two miscarried pregnancies as the result of AR; the other woman had not experienced a pregnancy at all. All other participants had borne children via either natural conception or via assisted conception. Fifty-seven percent of all participants had a child (or children) via assisted conception only. Twenty-nine percent of all participants had a mix of naturally conceived and assisted conception children in their families. Seven percent had only naturally conceived children. Just under one-third of participants had success on their first AR cycle and just over one-third had success with AR after between two and thirteen cycles with four to six cycles being the most common duration before success. Four women had experienced multiple births after AR – one set of triplets and three sets of twins. All other AR babies were singletons. Ten women had experienced miscarriages with most of these miscarriages being AR conceived pregnancies.

The decision to use assisted conception was often described in terms of the technology being a 'means to an end' (Ivy). Quite a few participants made comments along the lines of that their desire to have a baby meant that they 'didn't care what [they] had to do' (Jan). This was also the case for Ivy:

> *I think we were robotic almost... just got into automaton mode and did it fairly robotically...... Invasive personally but again, do you want to have a child or*

don't you? If it means that is what you have to go through... Just one of the many evils hopefully for the long term benefit. (Ivy)

For Ivy the prospect of motherhood offered by AR meant that she too would do whatever was necessary to achieve her aim, but should there be a need for people to *endure*?

For the proportion of women who had experienced natural conception after using assisted conception services, the following comments were typical and they indicate that the conflation of AR with natural conception in some AR marketing and general discourse is at odds with people's lived experiences:

> *It is quite a bizarre experience; it is so out of the normal... You don't realise how bizarre it is until you fall pregnant naturally and it just doesn't make sense afterwards...Just to wake up one morning and be pregnant as opposed to months and months of organisation and medication and timing and tablets and injections ; then to just wake up one morning and be pregnant, that is weird! It is almost science fiction compared to having gone through it manually so to speak. (Jane)*

> *It was incredible; I just couldn't believe how easy it was! It's amazing, I felt like a fraud! (Jan, laughing)*

> *...A natural conception – we were a bit stunned as to how that happened. (Jacquie)*

These distinctions between natural and assisted conception were also spoken of in terms of the quest to conceive a child via AR becoming 'impersonal' (Vikki) and some felt that 'there was no love attached' (Belinda) and that the 'romantic thing' of having a child had been absent from their AR experience.

> *It takes so much spontaneity out of your life and even right down to you knowing exactly when it is happening. There is no magic; you miss out on that because it has all been demystified... It is scientific, not natural. (Clarissa)*

> *I got onto IVF and scientifically conceived. (Jane)*

For these women, it seems that there was no effective ontological reconfiguration and their experiences of assisted conception were continually measured against expectations about natural conception. AR remained a technical process and they remained excluded as active moral agents and the transactional nature of the medical encounter thereby remained obscured (Shildrick 1997). Lindi however had been able to maintain a more positive experience of AR, possibly because some successful ontological choreography and deliberate humanising measures being incorporated such as having her partner closely involved and having the opportunity to express affection during embryo transfers:

What a powerful thing you are doing. You may be creating a new life and yes, we never found it clinical. We always found it incredibly moving and it made us really close. Larry would cuddle me while they were doing it and just felt really part of it. It was good (Lindi).

Lindi's comment reinforces the importance of assisted conception being regarded for what it is – a human process being undertaken by people who hope to become parents as a result and not as a mechanistic, fragmented process involving disembodied body parts In Lindi's case, the mutuality of relationships in the reproductive encounter and her agency had been respected and this had been experienced in a very positive way by Lindi and Larry.

So while most participants had redressed their childlessness one way or another at the time of interview in that most had successfully given birth to at least one child, some also had success in the form of embryos still in storage.

Embryos

At the time of the research interviews, one quarter of all participants still had embryos in storage and the majority were uncertain about the fate of their embryos. There were variations in how participants described their embryos with some regarding embryos in storage as family members, as full siblings to existing children while others viewed stored embryos as definitely 'potential' rather than actual albeit 'suspended' babies:

Those little embryos are us ... and that's sort of a bit weird. (Lily)

I probably know more than the average Jo... All these ethicists saying that we can't use embryos because they are a baby, well bullshit, they are not babies. How many of those embryos did I have that came to nothing? And I get cranky at them because I think they're putting it out there to people that they are throwing away babies and they are not to me, they are not. Even though every time an embryo went into me it was a baby on its way, I now realise that every embryo won't make a baby. (Josie)

Josie's comment illustrates her situated knowledge of some of the complexities that service users face in dealing with the storage of surplus embryos. For her, embryos only became potential humans once transferred to her body; the unitary, disconnected embryo-in-storage was not. Her comment underscores the transactional nature of reproduction with the woman's body being integral to the process of reproduction and without the capacity of a woman's body Josie did not consider the embryo to have potential personhood. Women's bodies then are seen here as indispensable in the reproductive process (Davis 2007), not as incubators (Shildrick 1997) but as central in reproducing humans.

177

Regardless of the status ascribed to embryos by participants, all described the decision-making about the fate of surplus embryos in storage as particularly vexing. The options available to most clients include donation for research, donation to other couples or disposal. For most service users in non-metropolitan areas, this actual range of options excludes donation for research due to research generally only being done at larger metropolitan clinics and regulations restricting the 'exchange' of embryos between clinics. Many participants were uncertain of the range of options and several said they wanted to donate their embryos to research despite this not actually being an option offered by their regional clinic. Several women said that they had not been adequately informed about storage fees as well as actual longer term options, psychosocial and emotional aspects, and that the most they ever got from their clinic was an invoice for the cost of storage:

> I'm not sure at the moment whether you can donate them to stem cell research... I think that's what I'd like to do...There's not a lot of information about what you can actually do...I hope you get a bit of counselling to deal with it because I don't think it is an easy decision... What the hell do you do with them? (Josie)

Josie's comment also indicates a need for access to psychosocial support to be accessible for people facing this type of decision – a need also reinforced by the literature (e.g. Fuscaldo, Russell and Gillam 2007; Burton and Sanders 2004). Likewise, none of the participants with embryos in storage wanted to donate their embryos to other couples for procreative use preferring instead to donate for research or to discard and this also mirrors the findings of several researchers (e.g. McMahon and Saunders 2007; de Lacey 2006).

Pregnancy, childbirth and postnatal experiences

Of those who offered descriptions of their pregnancies, five said they were unproblematic and ten participants described problems of one sort or another during their assisted-conception pregnancies. The most commonly reported problem was threatened miscarriage ('spotting' and bleeding) and one participant with a multiple pregnancy described placental insufficiency to one baby in the late stages of gestation. Many women described feeling anxious during their pregnancies and many attributed this, at least in part, to the anxieties surrounding the whole assisted conception experience. Many also described health practitioners expressing extra concern for their 'IVF pregnancy':

> You just realise that until you have got the baby in your arms, it is not here yet, you know? We all found pregnancy was pretty stressful because we'd wanted it for so long. (Sharon)

> In this area there are probably a lot of farmers' wives too, to my way of thinking, sure, when you fall pregnant naturally you don't know for six weeks

and you might be driving a tractor for those whole six weeks, but when you have done something like IVF there's too much riding on it... Once I was into the pregnancy I was very closely monitored and my doctor knew how much had gone into conception. Even though every pregnancy is special... this is a very important pregnancy and we have got to make sure everything goes incredibly right because what was involved in becoming pregnant through IVF is not that simple. (Jane)

When I went to the antenatal clinic it was always questioned 'is this a natural pregnancy?' No it's IVF - 'OK then we have to take special precautions'. I thought- why? No-one explained why. (Kylie)

I had been going to a specialist all through my pregnancy and he said 'I am not taking any chances; I will see you each week'. He would do an ultrasound each week because he had an ultrasound in his rooms. (Toni)

Along with recognition of the significant challenges involved in achieving success via assisted conception, the 'special-ness' of these pregnancies is in large part related to experiences of involuntary childlessness. But 'special-ness' could also arguably be related to the veneration of technology involved in the conception process and subsequent amplification of the role of 'science as father' and the consequent decline of women as central and active in the whole process (Lie 2002). It seems that for some participants, the emphasis on reproductive technology is sustained throughout the pregnancy and possibly extends to the childbirth experience as well. For instance, of those who offered information about their post-AR childbirth experience, four said they gave birth vaginally with limited or no intervention; eight had caesarean sections and four experienced premature delivery. Kylie and Jan specifically mentioned feeling 'pushed' by health professionals to accept what they perceived to be a greater than usual level of intervention throughout their pregnancies and childbirth experiences. Some participants commented on the impacts of assisted conception on their own perception of their capacity for natural, unassisted childbirth, indicating that for some women, confidence in their natural capacity was brought into question by their use of technology to conceive:

I didn't know if I could have a natural birth because I'd had the IVF treatment. (Tina)

I wanted to have a natural birth but the doctor said it was best to have a caesarean six weeks early. I wanted to wait. He told me that was the best thing for the twins but we nearly lost one of them. I said I wanted a natural birth and that was it, he walked out of the room and said he had more rounds to do. (Kylie)

These comments are consistent with a considerable body of literature on the overall impacts of reproductive technology on confidence levels, anxiety and depression (e.g. Verhaak et al. 2007; Eugster and Vingerhoets 1999). Similar impacts also appeared to

179

extend to the post natal period for a minority of the women who participated in this research with a few describing feeling 'low' in the post-natal period. One woman described 'bonding difficulties' with her child and felt that she 'should be over the moon' because she had 'waited so long, maybe I should be feeling something different' (Tina). Tina's comment illustrates the findings of Hammarberg et al. (2009) in relation to the added impacts of infertility and AR on some new mothers' confidence and their willingness to seek help. In particular, Tina's comment shows how the experiences of involuntary childlessness and AR can result in ongoing pressures to behave in a certain idealised way over and above the pressures felt by women with naturally conceived children. Another participant (Ivy) also described experiencing a 'torrid six months' after the birth of her child although she attributed this mainly to being 'very regimented and slowly learning to bend a bit' as well as 'the typical effects of sleep deprivation'.

Likewise the impacts of pregnancy loss appear to be amplified for many women when the pregnancy loss has been the result of a time of involuntary childlessness and use of assisted conception. Almost one-third of participants had experienced at least one miscarriage after AR with almost one-fifth of these women experiencing multiple miscarriages. For instance Judith had experienced repeated miscarriages after assisted conception but no successful live birth and for her the fact that she had achieved pregnancy, albeit short-lived, was some consolation in the overall experience of involuntary childlessness:

> *At least we can say to people who ask why we don't have kids – look, we gave it a go. I can turn around and say to them look, I've had miscarriages. And straight away people back off. (Judith)*

The decision to discontinue

Of the three women who were still using AR at the time of interview, all had one child via previous AR and no naturally conceived children. Of the five women who were unsure about the continuation of AR, four had experienced live birth via AR or natural conception and one woman had not experienced live birth at all. Twenty women (71%) had decided not to use further AR services and all but one of these women had experienced live birth either via previous AR or natural conception.

Most participants described difficulties in decision-making about the duration of AR use. Only three participants described having a clear limit on the duration of AR from the outset; most other participants who had decided to cease AR identified a range of reasons:

- Financial impacts too high (6 women) – *'we can't afford to go through it again' (Sue)*;
- Emotional costs too high (6 women);

- No desire for more children (6 women) – *'be happy with what you've got'* (Phoebe);
- Physical impacts too great / fear of side effects (5 women) – *'my body had taken too much of a toll'* (Phoebe);
- Age – (5 women) – *'my age was against me'* (Phoebe);
- No embryos in storage and reluctance to undergo more full stimulation IVF cycles (3 women);
- Relationship stress too great (2 women) – *'I want to look after my second marriage'* (Kerrianne);
- Medical advice to stop (2 women);
- Travel costs too high (1 woman).

The reasons stated for continuing with AR included:

- The 'glimmer of hope' (Lily) (8 women) – *'as long as we're trying there's hope'* (Lindi);
- Embryos still in storage (4 women) – *'I just feel like we need to give the embryo a chance'* (Elle);
- Ongoing desire for children (3 women) – *'we don't want an only child'* (Amber).

This range of responses corresponds with previous research findings on the factors taken into account by service users in decision-making about the duration of service use (e.g. Peddie et al. 2005; Arndt 2005). In addition, many of the participants in this research described their use of AR as 'almost addictive, like gambling I reckon' and that 'you just keep thinking about that the next time it will be right' (Jane) and 'all we need is a little luck' (Lindi). Some said they felt a pressure to justify their decision to discontinue to others:

> *Even when we gave up I felt for a while that I had to account to other people for why I only had one child, why didn't we keep going... I won't do that anymore... If you decide to give up, then do it, don't feel that you have to be accountable to other people. (Sharon)*

> *There was lots of pressure for me from my husband and from the IVF people to keep going, you know. (Kerrianne)*

With their decision to cease AR made, both Sharon and Amber described feelings relief and of reflection on the whole experience:

> *I'm feeling pretty happy now but it has been a big process, you know, coming from a decision to finish it off and all that sort of stuff really does make you examine yourself and your reason for things... It makes you wonder. (Sharon)*

> *I'm glad we're getting out of this now. (Amber)*

Recommendations from participants

Based on their experiential knowledge of assisted reproduction, what advice did participants have for other women contemplating its use? What did they think their clinics did well and what did they think the clinics need to improve on? What were their overall reflections on their experiences of AR? In order to explore some of these questions, each participant was asked to imagine that they had the opportunity to give advice and make recommendations to service providers and to potential service users. Almost all participants offered advice on a range of issues to both clinics and to potential service users with slightly more advice being directed at clinics (from 26 of the 28 participants) than to potential service users (from 25 of the 28 participants).

Recommendations to service providers

> *They are treating people who have so much riding on having a child they have wanted for a long time, they are putting all their effort and all their money into it and they expect a little bit of consideration, a little bit of warmth. (Kylie)*

> *...treat people with a bit of humanity, a bit of humanity. (Judith)*

The overarching theme for participants in this research was that AR needs to be consistently respectful and humane. The traditional medical model approach of doctor as expert and patient as passive recipient of expertise is not sufficient for this context, if indeed it is essential or sufficient in any health service delivery context.

Almost every participant had recommendations for changes to service delivery although one participant did not think that effective change was really possible given the context - 'you can dress it up all you like but the bottom line is it is still assisted conception' (Clarissa). While Lindi, Leonie and Toni were more positive about their experiences overall, they highlighted specific positive aspects of their actual clinic experience, such as friendly, supportive staff and the use of music for relaxation and recommended these measures for wider implementation in service delivery.

Improved timing, content and range of information

In chapter seven, participants' views on the adequacy of information actually provided to them in the early stages of service use was discussed. Here the focus is on participants' recommendations for improvement in this aspect of service delivery. Approximately 25% of participants made specific recommendations relating to information with the need for information to be paced appropriately and not rushed being common threads. The need for information to be broad-based and not solely biomedical was also identified as was the need for information to be consistent, clear and realistic – that AR 'should not be presented as a solution but as an alternative' (Judith). Two participants commented specifically on the need for more information to be provided on alternatives to reproductive technology. A recurring theme in the comments about information provision was the overarching need for women to be

treated as individuals and not 'like part of a herd of cattle' (Elle). Another dominant theme was for contact to be regular and to be part of a relationship with the service provider with some participants recommending continuity in care via a consistent contact person for each service user rather than 'being seen by a series of staff in quick succession' (Elle).

Several women who had used satellite clinics made comments specifically directed at the satellite model of service delivery. Common themes emerging from these comments relate to unmet needs for more personal, individualised, respectful treatment. Josie, Kate and Elle wanted other women to feel less like they had been 'shuffled through a series of staff in succession' (Josie) and for the pre-treatment cycle time to be used more effectively by satellite clinics. Elle commented that her clinic in future could use the intervening time between the quarterly 'active clinic' week to orientate new clients to the service, to offer introductory (and other) group information as well as support groups and in general, to build on staff-client relationships. Several women commented on the need for introductions to clinic staff to have occurred before the actual active treatment phase. As several women commented on the dehumanising effect of not knowing a clinician's name and/or not having had any prior contact with them at all before experiencing the actual procedure, this recommendation is very sensible.

> *I was concerned that I was talking to someone who didn't know me; you think they know my situation? (Kate)*

> *You should be able to meet the staff, get information, rather than wait until the actual treatment commences. (Elle)*

Likewise Jane recommended that the time between referral and AR service use be used more effectively to assess clients' overall health, lifestyle issues and support needs and to 'really make sure that couples are tuned into each other' (Jane).

In summary, in terms of information supplied to clients by clinics, according to participants the information needs to be:

- accurate, realistic, current and reliable;
- well-paced so as not to inundate service users;
- presented in accessible language and in a range of formats (e.g. text, diagrams, audiovisual material, internet links, etc);
- adequately followed-up through individual and/or group consultation time for questions, clarification and comments; and,
- comprehensive – medical and psychosocial content, other family formation options, complementary health, embryo storage options and longer term impacts.

Improvements to clinic facilities

Satellite clinic users in particular recommended that steps be taken to improve the level of privacy for service users in waiting and recovery areas. The practice of using other general health facilities for AR clinics was something women had recommendations about. Two women recommended that the local hospital's obstetrics unit should not be used in future for AR clinics. They regarded this practice as 'insensitive' but possibly unavoidable in smaller communities with limited health facilities (Ivy) and Kylie recommended that at the very least, women be offered more comfort in post-AR recovery areas, such as 'a cup of tea, a warm blanket' as well as more privacy. Two women commented on the need for better facilities for their partners in the sperm donation rooms, mainly in relation to increased privacy but also for 'better blue movies and magazines' (Carmen). A further two women recommended that photographic displays of babies be confined to reception areas if displayed at all and they both saw these anonymous photographs as offering hope for their own success in achieving pregnancy. But both recommended that procedure rooms be devoid of photographs of children, especially when the kinship ties of the children were clearly linked to the health professional providing the AR service. This indicates that the ontological choreography (Thompson 2005) often involved in assisted conception was challenged by these inescapable representations of traditional kinship ties:

> *You're lying on the bed and you're looking up at all these photos of him and his kids and I'd just think – why don't you put a picture of something else up there? You know? Lying there looking at all this stuff. Maybe from his point of view it was hopeful or something I don't know… I think it's probably not the place for showing off, I guess, like – look at all the kids I've got! You know? ….We really didn't need to see photos of his [the doctor's] kids'. (Jacquie, laughing)*

For women who had used metropolitan clinics while living in non-metropolitan areas considerable distance away, there were several specific recommendations:

- provide adequate accommodation information for remote clients;
- acknowledge and accommodate access and travel issues and incorporate this into timing of procedures and other appointments in order to streamline service use and reduce the amount of repeat travel – *'gee I'm glad we're driving all the way down here for a ten minute procedure' (Leonie); and,*
- greater use of facilities in client's home area (e.g. ultrasound, pathology) - 'you drive all that way for an ultrasound and it only takes them five minutes... we have an ultrasound here, they could send them pictures or something' (Jenny).

Clinic staff

In the initial stages of AR, participants identified the need for their relationship with the clinic to begin in a positive, respectful and honest manner to give the ongoing

relationship every chance of being constructive and rewarding, regardless of the eventual outcome of AR procedures. Of prime importance to participants was the need for clinics to 'make you feel like a person with a name' (Clarissa) and 'not as a generalisation' (Judith). This initial rapport was seen as a good foundation for being recognised as a valued part of the clinic:

> *You should walk in and they should know who you are. That is what you have to have and they need the amount of staff to be able to do that. (Lindi)*

Almost all (24) participants had comments relating to clinic staff with half of all comments being positive, especially in relation to the clinic nurse coordinators, and to a lesser extent in relation to reception and support staff. Most of these positive comments related to staff being prepared to take the time to explain things to service users and to respectful, individualised service. The recommendation arising from these comments is for this approach to service users to continue.

There were several participants unhappy with reception staff and some specific recommendations about this aspect of AR service delivery. Most recommendations centred on the need for receptionists to greet service users professionally, preferably by first-name, respectfully and with some sensitivity and compassion, given the nature of service use. Jacquie also commented on the need for reliable filing systems and record-keeping.

Seven women made specific recommendations about counselling with most of these recommendations relating to the need for better information about the role of counselling, improved access to counselling staff especially for follow-up support after unsuccessful cycles, pregnancy loss, decision-making about duration of AR use and embryo destination. Josie, for instance, recommended that the counsellor meet with all service users in the early phase of service use as she felt that this would make consultation with the counsellor more likely if such support was sought later on. Some participants expressed a desire for groups to be run, especially information-based groups. Phoebe suggested telephone counselling for out-of-town clients to supplement any on-site clinic counselling on-offer.

The bulk of negative comments were made in relation to medical practitioners at the various clinics. In terms of recommendations for improving doctors' quality of care, participants said that more effective communication skills were needed from the outset; that initial introductions and rapport-building needed attention and that ongoing communication, updates and explanations needed to be clear, accurate and respectfully delivered. The need for continuity of care and teamwork were also a recommended by several participants. For example, Sarah recommended that doctors take a few minutes before each meeting with service users to become familiar with the service user's details and to greet people by name and to indicate at least an overall

familiarity with that particular person's situation 'and not every three months come in and say – who are you and what's your story?' (Sarah).

Improvements in AR procedures

As discussed in detail in chapter eight, too many women had experienced unsatisfactory levels of care during AR procedures, most of them to do with lack of privacy and disrespectful, dehumanising treatment. Specific recommendations from participants included:

- More consistency in seeking informed consent from women for the presence of observers during procedures as well as more explanation of the roles of staff during procedures and the purposes of observation; 'I think there are some procedures that maybe they need to really think about what they are doing and why they need to be in the room' (Amber).
- Limits on the number of people in the procedure rooms;
- A more relaxed atmosphere in the procedure rooms, including the use of music, dimmed lighting, if practicable;
- Privacy during procedures – 'not to have others just walking in, like I experienced, that would have been great' (Kylie).

Again, all of these recommendations centre on respect for service users as active agents, as self-determining, fully entitled subjects and not as disembodied objects to be acted upon.

Other simple practical recommendations to enhance the experience included the use of relaxation music and/or music of the client's choice. Only a small number of clinics used by women in this research used music. Some requested a more sensitive approach to the way in which pornographic material is offered to male partners before sperm sample production; some participants objected to the presence of such material at all and the underlying assumption that it was required or appropriate in the first place, others asked for more variety in the material and a few suggested that there should be more comfortable and private sperm donation rooms available to their partners. Many appreciated being given the option of producing the sperm at sample at home, rather than at the clinic.

Thus most recommendations for improved service delivery centre on quality of care, client-centredness and humane treatment. What is highly significant in the non-metropolitan context however is that in order to access AR, these women also experienced the synchronisation of their menstrual cycles in the lead-up to each active clinic. For many women, this added to feelings of depersonalisation:

> *Like a great big herd of cattle, really. They had to synchronise everybody to the same day because the clinic only runs for a week every three months. Miss one*

clinic and you have to wait for another three months… They had everyone going like clockwork. (Elle)

It blew my mind to think there were that many women all doing IVF on the same day… There were twenty-odd women being done so he [the doctor] was probably thinking 'just another cow in the procession'. (Amber)

Synchronised cycles bothered me but you just do that to work towards it – it is one of the many evils for hopefully the long term benefit. (Ivy)

Not only had these women had to deal with the various losses involved with involuntary childlessness, the satellite model of service delivery then necessitated that they be 'processed' and standardised in terms of their bodily cycles, so that they would fit into the system. The loss of their body's natural, normal menstrual rhythms was not only an individualised loss but it also occurred in a collective context that they were fully aware of; that is that they were also synchronised with many other women's cycles in their small community. It is little wonder then that these women expressed a heightened need for humane and respectful treatment once they reached the procedural phase of AR. On this evidence, this model of service delivery could not be regarded as client-centred for these women.

Advice and recommendations for potential service users

Of the twenty-five women who had specific recommendations and advice for potential service users, most said that they would advise other women experiencing involuntary childlessness to seek help sooner rather than later, to 'get stuck in as quick as you can' (Sarah). Several participants said that ensuring good, basic physical health and a healthy lifestyle were also important factors in trying to redress childlessness. The most frequently offered advice related to emotional preparedness for the 'rollercoaster':

Making people fully aware that you are on a really, really high then on a really, really low, that there's sort of no middle ground because you're right up there with the clouds and then right back down again when you get a bad result. (Phoebe)

Advice about being prepared for AR procedures also figured in participants' responses:

If you don't like needles – forget it! Yeah because you're going to have needles in your stomach, needles in your arms, needles in your backside and you know there's going to be lots of needles! (Jacquie)

Don't be embarrassed. You're going to have to do a lot of embarrassing things like sit there with your legs up and all these people come in and there's no privacy. (Jenny)

187

Others felt that being well informed was highly important and urged other women to ask questions, pursue satisfactory, clear answers and to get their information from a range of reliable sources. Most felt that it was crucial to go in with 'eyes open' (Marion) and to be assertive – 'you're paying the money, you need to know what is going on and if you're not happy with it you tell them' (Anne). Kate advised that 'if you're not happy with one clinic, go to another' but for many women living outside metropolitan areas, this is often not a realistic option.

Many others commented on the importance of self-determination based on good information, firm decisions, asserting their client rights and providing feedback, even if unbidden by the clinic:

> *Make sure you feel comfortable with the people who are going to do the procedure. If you feel like anything is wrong or uncomfortable, yell out. (Kylie)*

> *If you're not comfortable with it, well it's your choice, then don't go ahead. (Belinda)*

Expectations of success need to be 'realistic' according to most participants and the need to access reliable information on success rates was identified as particularly important to guard against expecting it to 'happen straight away' (Sharon). Toni also felt that it was important to 'be prepared, it may not work' (Toni) and that it may be 'a long haul with lots of disappointments along the way' (Sarah) and that there's 'no guarantee' (Marion). Judith commented that assisted conception services:

> *...Should not be seen as a solution but as an alternative... It won't necessarily solve their problems... People have got to go into it knowing that they probably won't have a child or children from it and I think that you need to be more prepared for that. (Judith)*

However along with the need to be realistic, participants also advised others to try to remain positive and hopeful of success and to 'never give up' (Anne).

Jenny said that women need to be prepared for AR to be a constant in their life and to 'be ready to surrender your whole life to it because it's always in your mind'. While other participants wanted to alert women to the importance of maintaining a balance in all aspects of life to try to ensure that AR did not dominate in that way, to 'look at the big picture, look outside the square' (Leonie):

> *Keep things going that have got nothing to do with making babies... Keep your whole body healthy and balanced... If you just do the medical thing and are constantly pumping drugs into you that is not going to do your system any good. (Sharon)*

> *Have another focus because your mind gets to a point where your brain hurts I reckon just thinking about it. So yes, have something else going on at the same*

time, another goal that can keep you focused so that you know what is left if it doesn't work out... It's going to be a long, drawn-out thing. (Jane)

Maintaining strong partner and family relationships also emerged as a strong recommendation from participants. The importance of a strong support base and personal relationships was emphasised as was the need for both partners to be committed to AR because it was felt that the prospect of having one 'half-hearted' partner 'who wasn't with you 100%' would make AR 'awfully hard to face on your own' (Jane).

> *Make sure you both want a child as badly as each other. There is no point in one of you wanting a baby and the other one not being fussed or something because it is difficult and it is a strain on your relationship... Make sure you take time out for the relationship otherwise you will get to the end and there will be a child but no relationship. I would say to people nurse your relationship first. (Lindi)*

> *Have a partner who is going to support you and if your partner is not prepared to do that, don't do it. (Toni)*

In terms of other sources of support, several women said that t was necessary to 'surround yourself with people who understand' (Sharon) and to look for resources within the community such as counselling, support groups, internet resources and other women who have used AR. The common thread running through participants' comments here is the value in sharing experiential knowledge and the potential benefits of connecting with others for psychosocial support. These recommendations reinforce that reproduction is not a linear, individual, disembodied experience and that reproduction, whether it is assisted or not, inescapably occurs in a social context and in connection with other people.

In summary, the recommendations made by participants, whether about facilities, behaviour or practicalities, all echo the major recurring theme in participants' stories: the desire for a more consistent, holistic and respectful approach to assisted reproduction. Another overarching theme is the need for clinic practices to facilitate the ontological choreography involved in AR processes - privacy in particular. The need to place service users' needs at the centre of service delivery is clear and the non-metropolitan, satellite service delivery has some major issues to address in terms of quality care.

In the next, (concluding) chapter the broader implications of participants' experiential knowledge are explored in terms of overall service delivery, psychosocial support and quality of care. The strengths, limitations and contributions of this study are discussed and directions for further research are suggested.

Chapter 13 - Conclusion

This qualitative research project explored non-metropolitan women's experiences of assisted reproduction as well as their support needs and sources of support in the context of involuntary childlessness and assisted reproduction. In order to achieve this, first the broad context of involuntary childlessness and assisted reproduction was explored taking into consideration the dominant and competing ontological, methodological and epistemological bases for knowledge in this context. This concluding chapter discusses the findings and implications of this study in light of the themes emerging from the literature review. The conceptual framework, methodology, strengths and limitations of this study will be considered and suggestions for further research will be presented.

Key themes from the literature review

The review of literature established that there has been sustained interest in assisted reproduction for a considerable time. Assisted reproduction raises a wide range of issues and these implications and possibilities continue to pique the interest of researchers in humanities, social sciences and biomedical disciplines. The dominant discourse of assisted reproduction comes from the positivist, biomedical perspective despite there being a significant body of work critical of that dominance. Ethicists, feminists and other social researchers have raised concerns about various aspects of reproductive technology and in Australia the dominance of the biomedical approach is effectively sustained by regulatory structures. The dominant discourse in AR is also reflected in the types of research published with purely qualitative research, especially research from a feminist perspective, being the exception. Even in relation to social research, psychometric approaches appear to dominate much of the literature in the major AR journals.

Another general feature of research into women's reproductive health needs has typically focused on metropolitan populations. This leaves a gap in knowledge in relation to the needs of women living in non-metropolitan areas at some distance from major urban settlements.

These factors thus motivated this study and its aim to make a worthwhile contribution to the knowledge base of AR from a qualitative, feminist, post-structural perspective in relation to the lived experiences of non-metropolitan Australian women.

Revisiting the conceptual framework

From the outset, the need to consider assisted reproduction from an ontological perspective was evident. Without exploration at this level, consideration and critique of competing frameworks stays at a relatively superficial level and lacks force. The need to explore ontology is also indicated by the power and dominance of the

biomedical discourse in this context. It is intriguing that despite AR opening up a whole range of possible disruptions and challenges to modernist ontology and conventional epistemology that the dominant knowledge base and discourse have remained distinctly modernist, positivist and biomedical. This dominance means that at an ontological level, individuals are cast as disembodied, disconnected, unitary, linear entities. The over-reliance on knowledge derived from this ontological perspective impacts on the completeness, breadth and quality of that knowledge base because of the fundamental challenges posed to disembodiment and linearity by the creative and fluid potential of AR, as argued by Shildrick (1997), Braidotti (2005), Haraway (2004a), Thompson (2005) and others.

As discussed in the introductory chapter, this study resists Cartesian dualisms and binaries like nature/culture and above all, it helps to restore women's situated knowledge, to expose the ontological base of the dominant form of knowledge and to contribute to the re-envisioning of AR. An alternative ontological perspective is thus required so that interconnectedness, fluid subjectivity and women's agency can be recognised and valued. From this ontological base, alternative epistemology is validated. Experiential, situated knowledge is afforded a valued place within a firmer, more comprehensive knowledge base. Importantly, this broader knowledge base can facilitate an approach to service delivery in AR that is more responsive to the actual needs of those who use reproductive technology. Given this conceptual orientation, the justification for qualitative methodology is clear and directly seeking the views, experiences and support needs from a self-selected group of non-metropolitan Australian women via semi-structured, in-depth qualitative interviews is highly appropriate.

Strengths and limitations of the project

It would be an over-simplification to generate a list of the strengths and limitations of this study due to the very nature of qualitative enquiry. The beauty and value of qualitative, grounded, experiential, situated knowledge is its uniqueness, richness and sometimes even its apparent contradictions. These qualities are however often the basis upon which qualitative work is criticised. It is challenging to describe results and formulate recommendations from the research in a purely qualitative manner and not to be tempted to use terminology and units of measure better suited to quantitative, positivist methodology. Wherever possible the richness of what the participants in this study actually said has been offered and wherever appropriate, some indication of the relative importance or uniqueness or what was said has been offered. These quantitative indicators (percentages, raw numbers and proportions) should not be taken out of this qualitative context and should not be used to generalise in the conventional, positivist sense. So this 'limitation' would only in fact be a limitation if

generic assertions were drawn from the research and not appropriately qualified and contextualised.

Another limitation often identified in qualitative research is that it is not replicable or strictly verifiable. These criticisms emanate from an ontological viewpoint that validates only a particular form of epistemology and therefore only particular forms of methodology. Critics need to consider their own filters and acknowledge their ontological orientations and the limitations inherent in traditional approaches so as not to simplistically privilege a certain form of research and knowledge.

There is value in having a range of perspectives and points of view, a range of methods and thereby a range of forms of knowledge. The validity of qualitative enquiry stems from the participants' stories themselves as real and valuable accounts of a phenomenon. The validity of the researcher's analysis stems from how participants' information is presented, described and analysed in light of other views and ideas from the literature and from the researcher's perspective. A different researcher may well interpret participants' information in different ways and as long as the interpretation fits with what participants have offered in a logical, reasonable way, that too is part of the richness and creative potential of qualitative enquiry based on lived experiences. This is particularly valuable in the context of AR where qualitative research and phenomenology continue to be undervalued in dominant discourse.

Much of the value and contributions made by projects such as this emanates from the richness and range of information discovered in participants' stories, comments, memories and opinions. Qualitative approaches offer opportunities for lesser-heard voices to have some space for expression and empowerment. In qualitative research, the exceptional voices can be heard and not 'smoothed away' as they might be in more conventional approaches aiming for a neat, universal 'truth'. Without grounded enquiry, the nature of the knowledge base in AR remains limited and incomplete. For completeness a post-conventional knowledge base of AR would include conventional, positivist information as well as information from a phenomenological base, as argued by Haraway (1997), Shildrick (1997), Sprague (2005) and others.

A limitation of this study could be that all but two participants had been successful, one way or another, in achieving motherhood at the time of interview. The relative absence of women experiencing ongoing childlessness does mean that information on lived experiences from this perspective is thus limited. Perhaps the relative absence of these voices reflects an unwillingness to revisit unresolved and painful issues for these women - a reluctance to re-open old wounds. This limitation is however difficult to address given that participants were voluntary and self-selected. Purposeful recruitment would have been required in order to increase the proportion of participants still involuntarily childless. Strictly speaking, such purposeful recruitment

does easily fit with the type of qualitative method used in this study in that purposeful recruitment itself implies a desire for a representative sample, presumably for the purposes of generalisation. Again, this perceived limitation is at odds with the orientation of this study. This notwithstanding, it would be fruitful to hear more from women with such experience and future research could employ recruitment methods more likely to attract such volunteers. For instance, the advertisements and notices about this research were broadly aimed at any woman who had experienced AR and it attracted a reasonable range of women, as discussed in Chapters Six and Seven. But notices specifically aimed at those who remained childless after AR would yield a range of valuable experiential knowledge that would make a valuable and much-needed contribution.

However the relative absence of women experiencing ongoing involuntary childlessness could also be seen as adding weight to the themes that have emerged from this research. If this group of mostly successful women still expressed major concerns about aspects of AR and when many of these concerns echo first wave feminist critique from the late 1970s and early 1980s, then clearly there are serious issues that AR service providers need to address.

Likewise, experiential knowledge from a wider range of ethnic, cultural, relationship and socioeconomic backgrounds would make a significant contribution to the knowledge base. As discussed in Chapter Six, the participants in this research were quite homogenous in most demographic terms and additional, purposeful exploration of a diverse range of people's experiences is warranted. However, while Australia as a nation is multicultural and diverse, non-metropolitan Australia is much more homogenous (ABS 2008).

As most participants had ceased using reproductive technology, retrospectivity could be identified as another limitation. However *lived* experience is by definition past - although one's proximity to the events and experiences in question could undoubtedly affect the way it is recalled. For some, this could mean a softening of views and for others the opposite could be true. Again, strict accuracy in the detail of recalled events is not the aim and there is no claim being made that participants' experiential knowledge is somehow definitive, universal and representative of all women's experience. What has been identified in participants' stories are some commonalities, some contradictions and some exceptions but above all, richness. What unites, but not standardises, these women is the experience of involuntary childlessness, the use of reproductive technology, non-metropolitan location and a common body form.

As discussed in the methodology chapter, there was an inevitable power differential between researcher and participants and while every effort was made to approach interviews in a non-authoritative manner and for interviews to be participant-led, to

speak *with* and not *to* these women; there were some aspects where the power of the researcher was unavoidable. Specifically, the interviews only occurred because the researcher asked for volunteers in the first place; the researcher was not approached to undertake the study. The semi-structured interview schedule used was developed by the researcher with limited direct input from participants from the pilot interview. While the structure was loose enough to provide space for participants' stories to unfold, there was some generic structure overall, nonetheless.

Another power differential between researcher and participants was that the researcher chose not to disclose a great deal about personal circumstances during interviews; when such information was requested, minimal, generic, neutralising (though honest) responses were given. There was a multipurpose aim in this regard, namely to avoid personalising and shifting focus from participant to researcher and also to avoid disclosing the researcher's lack of experiential knowledge of AR and involuntary childlessness. Regardless of the merits of these aims, the imbalance between researcher and participants remains an accurate observation of the nature of the research process.

Key themes and new perspectives on assisted reproduction from this research

The impacts of involuntary childlessness and assisted conception on women and their partners have been well documented internationally over the years by a range of researchers using a variety of approaches. This study adds to the body of literature in general and it reinforces the importance of client-centredness as the basis for quality in service delivery regardless of location. Particular contributions made by this study relate to the additional factors often faced by non-metropolitan women in Australia due to locational disadvantage and modes of service delivery. This study also contributes to knowledge about relationships between service providers and service users, psychosocial support needs and policy implications.

Locational disadvantage and modes of service delivery

The additional impacts of service use for women in non-metropolitan areas include limited access to reproductive services options in the first place and extend to reduced allied health and support service options, due to access and availability limitations in Australian regional, rural and remote areas. The added costs and opportunity costs for non-metropolitan women using AR services are considerable and include travel and accommodation costs, amongst others things, as discussed in detail in Chapter Eight.

The non-metropolitan context presents challenges in the delivery of assisted conception services. Service provision should not be characterised by a commercial production-line, standardised approach and the emphasis in AR clinics, including satellite clinics, should not be on throughput and maximising numbers of women

'serviced' at the expense of humane processes. There are real opportunities for service providers to build on some existing practices that recognise the importance of respect and reproductive choice to the women and men who choose to use the service. There are real opportunities for satellite clinics in particular to make more effective use of their service delivery model to improve on the quality of care and to be truly client-centred. So while participants in this study appreciated being able to access AR in their local area, access should not be at the expense of respect for human dignity and worth.

However if opportunities for improved service delivery are to be operationalised there is clear need for an alternative, post-conventional paradigm in AR. The continued domination of biomedicine in this context cannot be justified in light of its incompleteness particularly in relation to lived experiences of assisted conception. The women who participated in this research indicate that their choice to use reproductive technology is far from disengaged, disconnected, passive or disembodied. The alternative paradigm needs to be built on a more inclusive, active, fluid, nomadic ontology that would more comprehensively reflect the phenomenon of assisted reproduction, the situated knowledge of service users, its considerable broader social impacts and collective concerns. As recommended by Rosi Braidotti (2005), such an alternative paradigm would recognise that women and their partners are decisive agents in assisted conception and on this basis it is less likely that humans will be regarded as disposable commodities in AR. Without such transformation, assisted reproduction remains vulnerable to the criticisms first raised by 'first wave' feminists, such as Klein (1989a&b), Corea (1988), Rowland (1988), and others.

As well as the generic locational disadvantages faced by service users, many of the women who used satellite clinics indicate that there are unique disadvantages associated with this service delivery model. The satellite service delivery model also offers some unique advantages or potential advantages too. Participants identified some practical steps that could be taken to improve the quality of service delivery by satellite clinics in regional areas and most of their recommendations centred on the opportunity for clinics to use the 'non-active' time between active clinic times (typically one clinic per three months per year) more effectively. The suggestions for better use of this time included using the time for a more thorough, less rushed orientation process for new clients, on re-orientation for continuing clients, on information-giving, and on using the time to establish and maintain a range of psychosocial supports. Significantly, all suggestions are essentially aimed at improving communication and *relationships* between service users and providers.

Another unique outcome regarding non-metropolitan service delivery is the practice of menstrual cycle synchronisation. If the satellite model is truly the only possible mode of service delivery in regional areas, then service providers must acknowledge the

context in which they are operating and the additional impacts of synchronisation on cohorts of women. To meet a reasonable standard and quality of care, satellite clinics evidently need to pay more attention to the support needs of their clients, not less. Service delivery in non-metropolitan Australia should not be approached in a manner that prioritises efficiency over quality of care. There are real opportunities for innovative, respectful and humane service delivery particularly with better use of time between 'active clinics' for relationship-building, orientation and information of clients.

The service provider/service user relationship

The importance of relationship-building is in fact the overarching need identified by all participants. This finding reinforces the need for a broader knowledge base and a more inclusive approach in the context of the delivery of reproductive services. It underscores the limitations of the biomedical model as the dominant knowledge base in this context and highlights the need for a more comprehensive epistemological base in reproductive services; a knowledge base that respectfully incorporates experiential, situated knowledge as well as the valuable and required knowledge offered by the biomedical model.

Thompson's (2005) notion of ontological choreography aimed to conceptualise the relationships and patterns of interaction in AR. While ontological choreography is an effective way to explore the various ways in which service users re-chart the story of their family's formation and kinship ties via assisted reproduction, it is less effective in conceptualising women's experiences of AR service delivery. *Choreography* implies a planned, cohesive effort, a series of interactive moves with all dancers' steps recognised as vital to complete the performance. Clearly, AR is still not often consistently choreographed in a way that validates experiential knowledge. Indeed at times, some women have experienced not so much of a dance, but found themselves thrown into a military-style formation march where they were required to fall into line. While ever the biomedical approach retains its almost exclusive dominance in AR, medical practitioners and their allies will continue to recognise their own steps as important; they will continue dancing their own dance, marching their own march, repetitive though it may often be. They will probably not recognise the need to adjust their rhythm and style to account for their various partners' needs; indeed they will be likely to remain largely oblivious to their partner's very existence. As such, the notion of choreography often fails to account for all of those interconnected and involved in the process and it is service users who are left out of meaningful calculations.

Many women's experiences could be encapsulated by the concept of ontological *dissonance* - meaning a lack of harmony or discord requiring some sort of resolution to achieve a more consonant state. The concept of dissonance also holds promise of more positive outcomes for often it is dissonance that makes something memorable,

unique and creative; it is only when discord is unresolved and when it dominates the overall experience and when consonance is not achieved, that the overall experience is unsatisfactory.

For those with more positive accounts of their experiences, there may well have been a period of dissonance, but adequate action had been taken towards achieving consonance to leave these women feeling that the experience was resolved and validating for them. The resolution often seems to come from these women being recognised as individuals with their own stories, their own unique situations, needs, personalities and dignity.

For some, a more consonant state was most likely experienced as involuntary childlessness was resolved either via successful AR or via natural conception. For some consonance seems to have been intrinsic to the AR experience in that they were treated with respect, dignity and humanity and they could thus recall it with positive regard. From what participants said it appears that while all hoped assisted conception would work for them, its real value rested in it being an active option with which the women engaged and by which they could at least try to redress involuntary childlessness.

Psychosocial support

In terms of support needs and based on the outcomes of this research and the existing body of literature, there is a clear case to be made for effective psychosocial support systems to be consistently incorporated into service delivery. By virtue of the range of needs identified by women and because the multidimensional impacts of service use, social workers are well placed to provide appropriate psychosocial support. The core values of social work and the breadth of the professional knowledge base would also be an ideal counterbalance to positivist approaches to other aspects of assisted reproduction. Social work and its concern for the micro, meso and macro levels of situations is a firmer basis for truly reforming AR services. The dominance of support workers coming from either a psychology or nursing background is more likely to reinforce the current dominant paradigm in AR, although the social work profession is not immune from uncritically adopting such approaches to 'clinical' practice and operating as agents of social control in this context.

As suggested by Blyth (2008c & 1999a), Dominelli (2002), Napier (1989) and others, the social work profession's framework for ethical, holistic practice is well placed to disrupt the dominant discourse of AR and to reclaim reproductive rights from the silencing and disempowering effects of biomedicine. A human rights framework would serve to emphasise the need for foundational assumptions about wholeness, interdependence, interconnectedness, diversity and broader community context to be

reinforced, and not to be overrun by the individualism of linear subject-object relations.

Policy implications

To achieve a more ethical, effective, holistic and responsive form of assisted reproduction ongoing contributions to knowledge from a range of epistemological bases need to be made. More biomedical knowledge is needed on the short, medium and long term impacts on women, their partners and any offspring conceived with the help of reproductive technology. More contributions to psychosocial knowledge are required, also from a range of epistemological bases. There is value in replicable, positivist approaches to some psychosocial issues in AR and there is a need for rich, experiential qualitative knowledge to ensure that service delivery is responsive to the actual needs rather than the assumed needs of service users.

Along with a firmer, more comprehensive knowledge base, the system of regulation in Australia needs to develop a correspondingly broader multidisciplinary base. More independent service-user representation would contribute to this as would a broader representation of professions and disciplines in regulatory bodies and on independent review panels. The continued dominance of biomedical and allied professions only serves to reinforce bias in the knowledge base and stymies creativity, responsiveness and potential for multidimensionality and improved quality in service delivery, articulated since the mid-1980s to the current time (e.g. Family Law Council 1985, in Fisher 1989; FSA 2004; ARTRC 2006).

Some specific policy and practice measures to better serve non-metropolitan service users in particular could include Medicare (or other systemic) reimbursement for travel and accommodation expenses as a means of offsetting some of the locational disadvantages faced by rural and regional Australians. Privately owned AR clinics could be required to pay a levy to fund a national, independent psychosocial support service for all service users. This service would ideally offer regular outreach visits to non-metropolitan areas especially to establish relationships with service users, then with ongoing counselling possibly delivered via telephone, online and/or video counselling. These practical measures would address some of the support needs identified in this research and would encourage a more multidisciplinary, holistic approach to clients' needs.

The national data collection framework also needs to be expanded to more effectively capture a wider range of information about service users, including qualitative information, longitudinal data, as well as information on access and equity issues. More detailed information on success rates per clinic would also aid in ensuring that public funds are directed towards the most clinically effective services and that potential clients could make more informed choices about service use, in areas where

clinic choice exists. Without this level of information for informed decision-making the 'fit' between service providers and service users remains an uneasy one with services being delivered in a largely privatised, marketised manner but without effective consumer choice for most people.

The expressed purpose of the ANZARD collection is to improve the quality of service delivery in AR and it is therefore imperative that the database is more comprehensive. If quality in service delivery encompasses safety, effectiveness as well as being client-focused, timely, equitable and efficient (Van Empel et al. 2008) then a correspondingly comprehensive, systematic database to assess these aspects of service delivery is required. Continuing to limit data to quantitative information and relying on clinics to self-report is hardly indicative of a client-centred, systematic, efficient approach to quality service delivery and is not a sound basis on which to claim clinical effectiveness. Reducing human reproduction to a series of inputs and outputs in this way does not adequately reflect the nature of the phenomena from any perspective.

The reporting mechanism in place for adverse outcomes in particular needs to be more effective and accurate in order to capture the range of experiences of service users. Current reliance on clinic self-reporting and on hospital admission data results in an incomplete picture about many important aspects of AR. Likewise better tracking of women and children post-AR would provide more longitudinal scientific knowledge of longer term impacts of the technology.

Directions for further research

Clearly more than technical proficiency is required in the delivery of any human service, but perhaps especially so in relation to reproductive health services not only because of the significant impacts of involuntary childlessness on individuals but also because of the wide-ranging societal ramifications of assisted reproduction (Bateman 2001; Blyth 1999a). And because the development of knowledge is 'a collective enterprise, built through dialogue' (Sprague 2005, p.180) it is desirable for dialogues to be ongoing with people who choose to engage with reproductive technology. Further independent research along these lines is therefore indicated and meaningful recognition of experiential knowledge and its incorporation into a revised multidisciplinary regulatory framework for assisted reproduction could help to transform the territory.

Research aimed at exploring service use from a wider diversity of clients' perspectives is also indicated. As indicated by participants, the impacts of involuntary childlessness and AR on men are under-researched areas. In many of the interviews for this project, the male partners would sometimes drift in or hover nearby and a few of these men were keen to offer insights gained from their experiences. Over two thirds of all participants specifically mentioned their partner's needs and many commented on the

lack of support available to partners throughout the AR experience. Further research to capture single women's experiences and same-sex couples' experiences is also needed in order to build a comprehensive knowledge base in this context.

Projects specifically focused on AR services operating as satellite clinics are also indicated by participants' comments. The model of service delivery used by many of these clinics appears to result in some specific issues for service users and to exacerbate some other impacts of AR. More studies to triangulate the themes that have emerged from this study are warranted so that the quality of service delivery in non-metropolitan areas can be maximised. In particular, privacy issues, the standard of facilities and shared facilities used by satellite clinics as well as clinic timing issues would be fruitful areas for further research.

Another important direction for future research is the exploration of alternatives to reproductive technology to redress involuntary childlessness. Participants in this research commented on the lack of information regarding alternatives. It would also be beneficial to hear more from those who choose not to pursue remedies to involuntary childlessness and to recognise the situated knowledge that these people have of the processes involved in accepting involuntary childlessness. Wider knowledge of these experiences could help alleviate some of the pronatalism still evident in this context and assist others to construct a different life story to what they had originally hoped for, as suggested by McCarthy (2008) and Napier (1989). Ongoing research into decision-making and the societal implications regarding surplus embryo destinations is also indicated, as is further research into the range of impacts of donor conception.

Conclusion

For there to be truly client-centred, high quality service delivery in assisted reproduction, service delivery must emanate from an appropriate knowledge base. The dominant biomedical knowledge base in this context does not adequately account for lived experiences and situated knowledge of AR. In particular, the dominant paradigm does not adequately account for interrelationships and collective concerns. What is required is a human rights framework where an ethics of care is broadly conceptualised in terms of proficiency and technical expertise as well as caring in terms of respect and nurture, as one participant said:

> *I wanted them to sort of nurture me, I suppose, but yeah, in the big picture of things I was just somebody coming in and going back out again. There have got to be other things that they could do. (Leonie)*

In working towards higher quality in AR it is not sufficient to simply incorporate or include service users' views into the existing paradigm; a *transformation* is required. Women's experiential knowledge should not be regarded as an optional addition to an

ontologically inappropriate form; the ontological base itself needs reconfiguration to adequately capture the nature of embodiment and agency in the context of assisted reproduction. Women are epistemologically indispensable to a reinvigorated, post conventional knowledge base in assisted reproduction. Without a re-envisioned knowledge base, without a human rights approach and with continued over-reliance on knowledge and practice based on disembodiment the risk that people will be treated inhumanely remains too high. At all levels of analysis, the importance of a multidimensional approach is indicated and this has been the central message from a considerable body of social, particularly feminist, research over the last three decades or so.

For the women who participated in this study, the ones who were most positive about their experiences indicated that being treated with dignity and respect were key aspects in the quality of care they received. The women who were least satisfied with AR consistently identified a lack of respect in aspects of service delivery as a major factor in their dissatisfaction. The reproductive technology sector has successfully established itself in a commercial sense and actively markets its services to attract business. And while the language of consumer choice is often used, the biomedical model still prevails and service users are not given adequate respect, choice and power. When world views collide in this way, service users are left frustrated that they have not been treated respectfully and service providers are perhaps puzzled that their 'patients' are often dissatisfied.

If the assisted reproductive service sector is truly committed to improving the quality of care, then serious effort will be made to restructure the regulatory system, to engage in multidisciplinary research and to recreate models of service delivery so that there is a genuinely consistent, multidisciplinary approach to the people who choose to use AR. Current examples of effective, client-centred approaches need to be amplified. Opportunities for innovative, humane practice need to be generalised across the sector. If there is not interest or serious effort towards these goals, one must ask what purpose does this resistance serve?

Too many of the women who participated in this study described substandard approaches to aspects of health care. The quest for better standards of care should not be left to individual service providers or to individual service users:

> *It's like being stuck in the middle of the ocean with not even a life raft. There's not a lot of humanity to it. I guess you have to find that for yourself and that could make or break some people. (Jane)*

In order to build a firmer foundation for high quality care, the assisted reproductive sector must undertake fundamental change. Central to this re-envisioned approach is respect for women's experiential knowledge.

References

Abboud, A, (2005, May 6). 'Inside the secret world of IVF'. *The Age.*

Adashi, E., Cohen, J., Hamberger, L., Jones, H., de Kretser, D., Lurenfeld, B., Rosenwaks, Z & Van Steriegem, A. (2000). Public perception on infertility and its treatment: An international survey. *Human Reproduction.* 15(2):330-334.

Alper, M., Brinsden, P., Fischer, R. & Wikland, M. (2002). Is your IVF programme good? *Human Reproduction.* 17(1):8-10.

Alston, M., Allan, J., Deitsch, E., Wilkinson, J., Shankar, J., Osburn, L., Bell, K., Muenstermann, I., Giorgas, D., Moore, E., Jennett, C., Ritter, L., Gibson, R., Wallace, J., Harris, J. & Grantley, J. (2006). Brutal neglect: Australian rural women's access to health services. *Rural and Remote Health.* 6:475. Retrieved March 1, 2006. http://www.rrh.org.au.

Arditti, R., Duelli-Klein, R. & Minden, S. (Eds.) (1984). *Test-tube women: What future motherhood?* Melbourne, Pandora.

Arndt, B. (2005). The baby chase. *The Australian Women's Weekly*. March 2005, pp. 171-177.

Australian Association of Social Workers (AASW) (1999). *AASW Code of Ethics*. ACT, AASW.

(2003). *Practice standards for social workers: Achieving outcomes.* ACT, AASW.

Australian Bureau of Statistics (ABS) (2006). *Australia and New Zealand Classification of Occupations*. Retrieved August 20, 2008. http://www.ausstats.abs.gov.au.

(2008). *Year Book Australia, 2008*. (1301.0). Retrieved May 26, 2009. http://www.abs.gov.au/AUSSTATS/abs@.nsf/bb8db737e2af84b8ca25717800157 01e/0AD628D49C8B6A73CA2573D20010FC5E?opendocument.

Australian Institute of Health and Welfare (AIHW) (2004a). Healthier babies born today using assisted reproductive technology. Media release, Canberra 1 October 2004. Retrieved October 11, 2004. http://www.aihw.gov.au/media/2004/mr041001.html.

(2004b). Rural, regional and remote health: A guide to remoteness classifications. Retrieved December 4, 2007. www.aihw.gov.au/publications.phe/rrrh-gtrc/rrh-gtrc-c01.pdf.

(2003). Assisted conception in Australia and New Zealand 2000/2001. Retrieved June 18, 2003. http://www. Npsu.unsw.edu.au/ac7high.htm.

Australia and New Zealand Infertility Counsellors' Association (ANZICA). (2008). *Membership information.* Retrieved November 17, 2008. http://www.anzica.org.

Australian Reproductive Technologies Review Committee (ARTRC). (2006). *Report of the Independent Review of Assisted Reproductive Technologies.* Retrieved

September 30, 2008.
http://www.health.gov.au/internet/main/publishing.nsf/Content/356F66F51D5D4163CA2571F50009EE7B/$File/artrc_report.pdf.

Baker, M. (2003). *Infertility, social exclusion and social policy.* Conference paper. Australian Social Policy Conference, 9-11 July 2003. Social Policy Research Centre, University of New South Wales. Retrieved August 7, 2003. http://www.sprcl.sprc.unsw.edu.au/aspc2003.

Balasch, J. (2000). Investigation of the infertile couple. *Human Reproduction*. 15(11):2251-2257.

Banks, S. (2006). *Ethics and values in social work.* Basingstoke, Palgrave MacMillan.

Baranov, D. (2008). Biomedicine: An ontological dissection. *Theory, Medicine and Bioethics.* 29:235-254.

Barlow, D. (2002). The children of assisted reproduction – the need for ongoing debate. Editorial. *Human Reproduction.* 17 (5): 1133-1134.

Barnby, K. (1995). *The labours of Eve: Women's experience of infertility.* London, Boxtree.

Bateman, S. (2001). 'When reproductive freedom encounters medical responsibility: Changing conceptions of reproductive choice'. In *World Health Organisation Current practices and controversies in assisted reproduction*. Report of the Meeting on Medical Ethical and Social Aspects of Assisted Reproduction. WHO Switzerland. 17-21 September 2001.

Bell, A. (2009). 'It's way out of my league': Low income women's experiences of medicalised infertility. *Gender and Society*. 23: 688-709.

Benson, K. (2008, October 17). Putting kids on ice. *Sydney Morning Herald.*

Berman, A. (2006). *Sex@6PM: A personal journey through IVF.* Sydney, New Holland Publishers.

Birenbaum-Carmeli, D. (2003). Contextualising a medical breakthrough: An overview of the case of IVF. *Health Care for Women International*. 24(7):591-607.

Blackburn-Starza, A. (2008). 'Victorian parliament approves equal access to IVF'. Retrieved November 12, 2008 from http://www.ivf.net/ivf/victorian_parliament_approves_equal_access_to_ivf-o3754-en.html.

Blyth, E. (1999a). The social work role in assisted conception. *British Journal of Social Work,* 29, pp. 727–740.

Blyth, E. (1999b). Secrets and lies: Barriers to the exchange of genetic origins information following donor assisted conception. *Adoption and Fostering.* 23(1):49-58.

Blyth, E. and Farrand, A. (2005). Reproductive tourism – a price worth paying for reproductive autonomy? *Critical Social Policy*. 25:91.

Blyth, E. & Golding, B. (2008). Egg sharing: A practical and ethical option in IVF? *Expert Review of Obstetrics and Gynecology.* 3(4): 465-473.

Blyth, E. & Moore, R. (2001). 'Involuntary childlessness and stigma. In T. Mason, C. Carlisle and E. Whitehead (Eds.). *Stigma and Social Exclusion in Healthcare.* London, Routledge, pp.217-225.

Blyth, E. (2007a). *To Be or Not To Be: A Critical Appraisal of the Welfare of Children Conceived through New Reproductive Technologies.* Conference paper presented at the Nobody's child, everybody's children conference, Malaspina University College, May 24-26, 2007. Retrieved October 22, 2008 from http://www.mala.ca.

Blyth, E. (2007b). Assisted reproduction: What's in it for children? *Children and Society.* 4(2):167-182.

Blyth, E. (2008a). Fertility patients' experiences of cross-border reproductive health care. *Online survey.* Retrieved September 30, 2008 from Http://www.survey.bris.ac.uk/hud/access.

Blyth, E. (2008b). To be or not to be? A critical appraisal of the welfare of children conceived through new reproductive technologies. *International Journal of Children's Rights.* 16(4): 505-522.

Blyth, E. (2008c). Inequalities in reproductive health: What is the challenge for social work and how can it respond? *Journal of Social Work.* 8:213.

Blyth, E., Burr, V. and Barrand, A. (2008). Welfare of the child assessments in assisted conception: A social constructivist perspective. *Journal of Reproductive and Infant Psychology.* 26(1): 31-43.

Bourdieu, P. (2001). *Masculine domination.* Cambridge*,* Blackwells.

Bowles, W., Collingridge, M., Curry, S. & Valentine, B. (2006). *Ethical practice in social work: An applied approach*. Maidenhead, Open University Press.

Braidotti, R. (1991). *Patterns of dissonance: A study of women in contemporary philosophy.* Cambridge, Polity Press.

Braidotti, R. (1994). *Nomadic subjects: Embodiment and sexual difference in contemporary feminist theory.* New York*,* Columbia University Press.

Braidotti, R. (2005). A critical cartography of feminist postmodernism. *Australian Feminist Studies*. 20(47):169-180.

Braidotti, R. (2006). *Transpositions: On nomadic ethics*. Cambridge, Polity.

Brinsden, P. (Ed.) (1999). *A textbook of in-vitro fertilization and assisted reproduction: The Bourn Hall guide to clinical and laboratory practice.* Carnforth, Parthenon.

Brod, M., Verhaak, C., Weibunga, C., Gerris, J. and Hoomar, E. (2009). Improving clinical understanding of the effect of ovarian stimulation on women's lives. *Reproductive Biomedicine Online.* 18(3):391-400. Retrieved March 9, 2009 from http://rbmonline.com.

Bryant, J., Sullivan, E. & Dean, J. (2004). *Assisted reproductive technology in Australia and New Zealand 2002.* AIHW Cat. No. PER 26. Sydney: Australian Institute of Health and Welfare National Perinatal Statistics Unit (Assisted Reproductive Technology Series No.8).

Burfoot, A. (1990). The normalisation of a new reproductive technology. In McNeil, M., Varcoe, I. & Yearley, S. (Eds.). *The new reproductive technologies.* New York, St Martin's Press.

Burton, P. & Sanders, K. (2004). Patient attitudes to donation of embryos for research in Western Australia. *Medical Journal of Australia*. 180(11):559-561.

Butler, J. (1990). *Gender Trouble: Feminism and the subversion of identity.* New York. Routledge.

Butler, J. (1993). *Bodies that matter: On the discursive limits of 'sex'.* New York, Routledge.

Campagne, D. (2006). Should fertilisation treatment start with reducing stress? *Human Reproduction.* 21(7):1651-1658.

Chambers, G., Chapman, M., Grayson, N., Shanahan, M. & Sullivan, E. (2007). Babies born after ART treatment cost more than non-ART babies: A cost analysis of inpatient birth-admission costs of singleton and multiple gestation pregnancies. *Human Reproduction*. 22 (12): 3108-3114.

Cheers, B. (1998). *Welfare bushed: Social care in rural Australia*. Aldershot, Ashgate.

Chen, T., Chang, S., Tsai, C. & Juang, K. (2004). Prevalence of depressive and anxiety disorders in an assisted reproductive technique clinic. *Human Reproduction.* 19(10):2313-2318.

Christopher, L. (2006, September 28). Surplus to requirements. *The Age*. Retrieved October 22, 2008 from Http://www.theage.com.au.

Commonwealth Office of the Status of Women. (2002). *Women in Australia, 2001*. Canberra, Australian Government Printing Service.

Conroy, S. (2003). A pathway for interpretive phenomenology. *International Journal of Qualitative Methods.* 2(3). Retrieved May 3, 2006. Http://www.ualberta.ca/%7Eiiqm/backissues/2_3/HTML/conroy.htm.

Corea, G. (1988). What the king cannot see. In Hoffman Baruch, E., D'Adamo, A. Seager, J. (eds.) *Embryos, ethics and women's rights: Exploring the new reproductive technologies.* London, Haworth.

Corradi, L. (2008). Redefining 'reproductive rights': An eco-feminist perspective on in vitro fertilisation, egg markets and surrogate motherhood. *Advances in Gender Research.* 12:245-273.

Crowe, C. (1985). Women want it: In vitro fertilisation and women's motivations for participation. *Women's Studies International Forum*. 8(6):547-552.

Daniluk, J. (2001). If we had it to do over again…: Couples reflections on their experiences of infertility treatments. *Family Journal,* 9(2), pp. 122-133.

Davis, K. (2007). Reclaiming women's bodies: Colonialist trope or critical epistemology? *The Sociological Review.* 55(1):50-64.

Daya, S. (2005). Life table (survival) analysis to generate cumulative pregnancy rates in assisted reproduction: Are we overestimating our success rates? *Human Reproduction.* 20(5): 1135-1143.

De Lacey, S. (2007). Decisions for the fate of frozen embryos: Fresh insights into patients' thinking and their rationales for donating or discarding embryos. *Human Reproduction.* 22(6):1751-1758.

De Lacey, S. (2006). Patients' decisions for residual embryos: Outcomes of a qualitative follow-up study of IVF patients in South Australia. *Abstracts of 22nd Annual Meeting of the European Society of Human Reproduction,* Czech Republic, 18-21 June 2006. Retrieved June 28, 2006. Http://www.humrep.oxfordjournals.org.

De Liz, T. & Strauss, B. (2005). Differential efficacy of group and individual/couple psychotherapy with infertile patients. *Human Reproduction.* 20(5):1324-1332.

Denzin, N. & Lincoln, Y. (2000). *The Sage Handbook of Qualitative Research*. Thousand Oak, Sage.

Department of Health and Ageing. (2006). *Australian Government Response to the Report of the Independent Review of Assisted Reproductive Technologies*. Canberra, Australian Government Printing Service.

Department of Human Services DHS (South Australia), (2004). *Legislation and ART.* Retrieved January 27 2004. http://www.dhs.sa.gov.au/reproductive_technology/legislation.asp .

Diaz, C. (2002). Conversational heuristic as a reflexive method for feminist research. *International Journal of Sociology.* 12(2):249-255.

Dickens, B. (2001). 'Ethical issues arising from the use of reproductive technologies'. In *World Health Organisation Current practices and controversies in assisted reproduction*. Report of the Meeting on Medical Ethical and Social Aspects of Assisted Reproduction. WHO Switzerland. 17-21 September 2001.

Diesfield, K. (1999). Review of Thompson, M. *Reproducing narrative: Gender, reproduction and law.* In *Journal of Medical Ethics,* 25(6), pp. 554-555.

References

Djerassi, C. (1999). Sex in an age of mechanical reproduction. *Science,* 285(5424), p. 53.

Dominelli, L. (2002). 'Glassed-in': Problematising women's reproductive rights under the new reproductive technologies. In Adams, R., Dominelli, L. & Payne, M. (Eds.) *Critical practice in social work.* London, Macmillan.

Dyer, S., Abrahams, N., Mokoena, N., & Van Der Spuy, Z. (2004). 'You are a man because you have children': Experiences, reproductive health knowledge and treatment-seeking behaviour among men suffering couple infertility in South Africa. *Human Reproduction*. 19(4):960-967.

Emery, M, Beran, M., Darwiche, J., Oppizzi, L., Joris, V., Capel, R., Guex, P. & Germond, M. (2003). Results from a prospective, randomised, controlled study evaluating the acceptability and effects of routine pre-IVF counselling. *Human Reproduction.* 18(12): 2647-2653.

Eugster, A. & Vingerhoets, A. (1999). Psychological aspects of in-vitro fertilisation: A review. *Social Science and Medicine.* 48:575-589.

Ewing, C. (1992). *Manufacturing babies: What reproductive technologies mean to women.* National Women's Consultative Council. Commonwealth of Australia. Canberra, Australian Government Printing Service.

Fertility Society of Australia (FSA) (2009). *Homepage*. Accessed 2 October 2009 www.fsa.au.com

(2005). *Accreditation status ART Centres Australia and New Zealand* . Retrieved April 27, 2005.http://www.fsa.au.com/apps/RTAC_sites/centres.php.

(2004) *President's Report* 2003. Retrieved January 27, 2004. http://www.fsa.au.com/news/inside.php?ID=42

(2002). *Code of practice for centres using assisted reproductive technology* (Revised April 2002). Retrieved May 2, 2005. http://www.fsa.au.com/pdfs/RTAC/guidelines-2002.pdf.

Fekkes, m., Buitenijk, S., Verrips, G., Braat, D., Braeways, A., Dolfing, J., Kortman, M., Leerentveld, R. & Macklon, N. (2003). Health-related quality of life in relation to gender and age in couples planning IVF treatment. *Human Reproduction.* 18(7): 1536-1543.

Fertility Society of Australia (FSA) (2009). List of Accredited IVF Clinics, Australia. Retrieved May 23, 2009. www.http://fertilityaustralia.com.au/rtac/accredited-units.

Field, D. (2008). Infertility facts thin on the ground. *The World Today*, Tuesday 21 October 2008. *ABC Online.*Retrieved October 23, 2008. http://www.abc.net.au.

Firestone, S. (1970).*The dialectic of sex: The case for feminist revolution.* New York, Morrow.

Fisher, A. (1989). *IVF: The critical issues.* Melbourne, The Book Printer.

Ford, N. (2008). A catholic ethical approach to human reproductive technology. *Ethics, Bioscience and Life.* 17(3).Retrieved November 7, 2008. http://www.RBMonline.com.

Foucault, M. (2003).*The birth of the clinic: An archaeology of medical perception*. London, Routledge.

Frame, T. (2008). *Children on demand: The ethics of defying nature.* Sydney, University of New South Wales Press.

Franklin, S. (1997). *Embodied progress: A cultural account of assisted reproduction.* London, Routledge.

Franklin, S. & Ragone, H. (Eds.) (1998). *Reproducing reproduction.* Philadelphia, University of Pennsylvania Press.

Fuscaldo, G., Russell, S. & Gillam, L. (2007). How to facilitate decisions about surplus embryos: Patients' views. Human Reproduction. 22(12):3129-3138.

Garceau, L., Henderson, J., Davis, L., Petrou, S., Henderson, L., McVeigh, E., Barlow, D., & Davidson, L. (2002). Economic implications of assisted reproductive techniques: A systematic review. *Human Reproduction,* 17 (12): 3090 – 3109.

George, K. (2008). Women as collateral damage: A critique of egg harvesting for cloning research. *Women's Studies International Forum.* 31(4):285-292.

Gerodetti, N. & Mottier, V. (2009). Feminism(s) and the politics of reproduction: Introduction to special issue on 'Feminist Politics of Reproduction'. *Feminist Theory.* 10: 147-152

Ginsburg, F. & Rapp, R. (1995). *Conceiving the new world order: The global politics of reproduction.* Berkeley, University of California Press.

Glaser, B. (2002). Conceptualisation: On theory and theorising using grounded theory*. International Journal of Qualitative Methods*, 1(2). Article 3. Retrieved 8/5/07. http://www.ualberta.ca/~ijqm/

Gleicher, N. & Barad, D. (2006). Unexplained infertility: Does it really exist? *Human Reproduction.* 21(8): 1951-1955.

Golombok, S., Breways, A., Giavazzi, M., Guerra, D., MacCallum, F. & Rust, J. (2002). The European study of assisted reproduction families: The transition to adolescence. *Human Reproduction.* 17(3):830-840

Gooch, L. (2003). A family born of determination. *The Sunday Age*, 'News' section, 20th July 2003, p.5.

Gore, A. & Lavender, B. (Eds). (2001). *Breeder: Real-life stories from the new generation of mothers.* Toronto, Seal.

References

Gosden, R. (2000). New options for mothers. *The Futurist,* 34(2): 26.

Greer, G. (1984). *Sex and destiny: The politics of human fertility.* Richmond, Heinemann.

Greer, G. (1999). *The whole woman*. London, Transworld.

Groenewald, T. (2004). A phenomenological research design illustrated. *International Journal of Qualitative Methods.* 3(1). Article 4. Retrieved 13 Sept 2005 from http://www.ualberta.ca/~iigm/backissues/3_1/pdf/groenewald.pdf.

Gupta, J. (2006). Towards transnational feminisms: Some reflections and concerns in relation to the globalisation of reproductive technologies. *European Journal of Women's Studies.* 13:23.

Gupta, J. & Richters, A. (2008). Embodied subjects and fragmented objects: Women's bodies, assisted reproduction technologies and the right to self determination. *Bioethical Inquiry.* 5:239-249.

Haase, J. (2007). Informed decision-making in reproductive technology: What is the role of counselling? Conference paper presented at the Nobody's child, everybody's children conference, Malaspina University College, May 24-26, 2007. Retrieved 22 Oct 2008 from http:// www.mala.ca.

Hamilton, M. (2000). Ethics in infertility treatment. *Scottish Journal of Healthcare Chaplaincy.* 3(1):9-14.

Hammarberg, K., Astbury, J., & Baker, H. (2001). Women's experience of IVF: A follow-up study. *Human Reproduction* 16(2):374-383.

Hammarberg, K., Fisher, J. & Rowe, H. (2008). Women's experiences of childbirth and post-natal healthcare after assisted conception. *Human Reproduction.* 23(7):1567-1573.

Hammarberg, K., Rowe, H. & Fisher, J. (2009). Early post-partum adjustment and admission to parenting services in Victoria, Australia after assisted conception. *Human Reproduction.* 23(11): 2801-2809.

Hammer-Burns, L. (1999). Genetics and infertility: psychosocial issues in reproductive counselling. *Families, Systems and Health,* 17(1):87.

Hansen, M., Kurinczuk, M., Bower, C., Webb, S. (2002).The risk of major birth defects after intracytoplasmic sperm injection and in vitro fertilisation. *New England Journal of Medicine,* 346(10): 725-730.

Haraway, D. (1988). Situated knowledges. *Feminist Studies.* 3:575-599

Haraway, D. (1989). *Primate visions*: *Gender, race and nature in the world of modern science.* New York, Routledge.

Haraway, D. (1991). *Simians, cyborgs and women: The reinvention of nature.* New York, Routledge.

Haraway, D. (1997). *Modest_Witness@Second_Millennium.FemaleMan©_Meets_OncoMouse™: Feminism and technoscience.* New York, Routledge.

Haraway, D. (2000). *Birth of the kennel.* A lecture by Donna Haraway, European Graduate School, New York, August 2000. Retrieved 11 Oct 2007 from, http://www.egs.edu.

Haraway, D. (2004a). 'A manifesto for cyborgs: Science, technology, and socialist feminism in the 1980s'. In Haraway, D. 2004. *The Haraway Reader.* New York, Routledge.

Haraway, D. (2004b). Situated knowledges: The science question in feminism and the privilege of partial perspective. In Harding, S. *The feminist standpoint theory reader: Intellectual and practical controversies.* London, Routledge.

Haraway, D. (2008). *When species meet.* Minneapolis, University of Minnesota Press.

Harding, S. (1986). *The science question in feminism.* New York, Cornell University Press.

Harding, S. (1991). *Whose science? Whose knowledge? Thinking from women's lives.* New York, Cornell University Press.

Harding, S. (Ed). (2004). *The feminist standpoint theory reader: Intellectual and practical controversies.* London, Routledge.

Hartsock, N. (1985). *Money, sex and power.* Boston, North-eastern University Press.

Health Insurance Commission (HIC). (2005). Medicare Australia. Retrieved 10 March 2005 from Http://www.hic.gov.au.

Heidegger, M. (1975). *The basic problems of phenomenology.* Bloomington, Indiana University Press.

Hellwege, J. (1999). Genetics, reproduction, and the law. *Trial,* 35(7):20.

Helmerhorst, F., Perquin, D., Donker, D. & Keirse, M. (2004). Perinatal outcome of singletons and twins after assisted conception: A systematic review of controlled studies. *British Medical Journal.* 328:261-264.

Hepburn, L. (1992). Ova-dose: *Australian women and the new reproductive technology.* Sydney, Allen & Unwin.

Hoffman Baruch, E., D'Adamo, A. Seager, J. (Eds). (1988). *Embryos, ethics and women's rights: Exploring the new reproductive technologies.* London, Haworth.

Husserl, E. (1999). *Cartesian meditations: An introduction to phenomenology.* Dordrecht, Klewer Academic Publishers.

Inge, G., Brinsden, P. & Elder, K. (2005). Oocyte number per live birth in IVF: Were Steptoe and Edwards less wasteful? *Human Reproduction.* 20(3):588-592

Inhorn, M. (2003a). The worms are weak: Male infertility and patriarchal paradoxes in Egypt. *Men and Masculinities.* 5 (3), pp.236 -256.

Inhorn, M. (2003b). Global infertility and the globalisation of new reproductive technologies: Illustrations from Egypt. *Social Science and Medicine.* 56:1837-1851.

Inhorn, M. & Birenbaum-Camreli, D. (2008). Assisted reproductive technologies and cultural change. *Annual Review of Anthropology.* 37:177-196.

Inhorn, M. & Van Balen, F. (Eds). (2002). *Infertility around the globe: New thinking on childlessness, gender and reproductive technologies.* Berkeley, University of California Press.

Irigaray, L. (1984). *An ethics of sexual difference.* New York, Cornell University Press.

Irigaray, L. (1985a). *Speculum of the other woman.* New York, Cornell University Press.

Irigaray, L. (1985b). *The sex which is not one.* New York, Cornell University Pres

Jansen, R. (1999). Sex, reproduction and impregnation: By 2099 let's not confuse them. *Medical Journal of Australia.* 171:666-667.

Jones, H., Cohen, J., Cooke, I. & Kempers, R. (Eds.) (2007). International Federation of Fertility Services Surveillance 2007. Fertility and Sterility. 87(1):S1-67.

Kainz K. (2001). The role of the psychologist in the evolution and treatment of infertility. *Women's Health Issues.* 11(6):481-485.

Kellett, U. (1997). Heideggerian phenomenology: An approach to understanding family caring for an older relative. *Nursing Inquiry.* 4: 57-65.

Kent, J. (2000). *Social perspectives on pregnancy and childbirth for midwives, nurses and the caring professions.* Buckingham, Oxford University Press.

Kerin, J. (1999). The matter at hand: Butler, ontology and the natural sciences. *Australian Feminist Studies. 14*(29):91-104.

Kevin, C. (2005a). Families on the frontier. *Griffith Review.* Edition 10 (Family Politics). Brisbane, Griffith University.

Kevin, C. (2005b). Maternity and freedom: Australian feminist encounter with the reproductive body. *Australian Feminist Studies*. 20(46): 3-15.

Kirejczyk, M. (2008). On women, egg cells and embryos: Gender in the regulatory debates on embryonic research in the Netherlands. *European Journal of Women's Studies.* 15(4):377-391.

Klein, R. (Ed). (1989a) *Infertility: Women speak out about their experiences of reproductive medicine.* Sydney, Pandora.

References

Klein, R. (1989b). *The exploitation of a desire: Women's experiences with in vitro fertilisation.* Geelong*,* Deakin University Press.

Klein, R. (1990). IVF research: A question of feminist ethics. *Reproduction and Genetic Engineering: Journal of International Feminist Analysis*. 3(3).

Klein, R. (2008). From test tube women to bodies without women. *Women's Studies International Forum*. 31(3):157-175.

Koch, L. (1990). IVF: An irrational choice? *Reproductive and Genetic Engineering: Journal of International Feminist Analysis.* 3(3).

Kolata, G. (2002). Treatments for infertility are studied for problems. *New York Times.* 7/3/02, p.16.

Koonin, R. & Napier, L. (2000). 'Working with self-help'. *Women in Welfare Education.* 4:11-22. Australian Association for Social Work and Welfare Education.

Kovacs, G. (1996). Assisted reproduction: A reassuring picture. *Medical Journal of Australia* 164:628-630. Retrieved 27 Nov 2003 from http://www.mja.com.au.

Kovacs, G., Morgan, g. Wood, E., Forbes, C. & Howlett, D. (2003). Community attitudes to assisted reproductive technology: A 20-year trend. *Medical Journal of Australia,* 179(10): 536-538.

Labett, T. (2006). *Fertility study: Attitudes, experiences and behaviours of the Australian general public*. For the Fertility Society of Australia. Labett Research & Marketing Ltd. Retrieved 8 Nov 2007 from http://www.abc.net.au.

Lambert, R., (2002). Safety issues in assisted reproduction technology. *Human Reproduction,* 17(12): 3011-3015.

Lambert, R. (2003). Safety issues in assisted reproductive technology: Aetiology of health problems in singleton ART babies. *Human Reproduction,* 18(10), pp. 1987 – 1991.

Langdridge, D. & Blyth, E. (2001). Regulation of assisted conception services in Europe: Implications of the new reproductive technologies for 'the family'. *Journal of Social Welfare and family Law.* 23(1):45-64.

Lechner, L., Bolman, C. & Van Dalen, A. (2007). Definite involuntary childlessness: Associations between coping, social support and psychological distress. *Human Reproduction.* 22(1):288-294.

Leger, L. (2007). A critique of NRGTS that examines issues of safety, consent, reproductive health and prevention. Conference paper presented at the Nobody's child, everybody's children conference, Malaspina University College, May 24-26, 2007. Retrieved 22 Oct 2008 from http:// www.mala.ca.

Leiblum, S., Aviv, A. & Hamer, R. (1998). Life after infertility treatment: A long term investigation of marital and sexual dysfunction. *Human Reproduction.* 13(12):3569-3574.

Lemmens, G., Enzlin, P., Bakelants, E., Vanderschoren, D., Hooghe, T. & Demyttenaere., K. (2004). Coping with infertility: A body-mind group intervention programme for infertile couples. *Human Reproduction.* 19(8):1917-1923.

Lie, M. (2002). Science as father? Sex and gender in the age of reproductive technologies. *The European Journal of Women's Studies,* 9(4):381-399.

Lorber, J. (1988). In vitro fertilisation and gender politics. In Hoffman Baruch, E., D'Adamo, A. Seager, J. (Eds). *Embryos, ethics and women's rights: Exploring the new reproductive technologies.* London, Haworth.

Lupton, D. (2004). *Medicine as culture.* London, Sage.

Maher. (2001). The productivities of pregnancy: Reviewing medical technologies and feminist critiques. *Hecate,* 27(2): 135 – 146.

Masters, J. (2000). *The rollercoaster: A country couple's ride with IVF*. Adelaide, Wakefield.

McCarthy, M. (2008). Women's lived experience of infertility after unsuccessful medical intervention. *Journal of Midwifery and Women's Health.* 53(4):319-324.

McMahon, C., Gibson, F., Leslie, G., Saunders, D., Porter, K. & Tennant, C. (2003). Embryo donation for medical research: attitudes and concerns of potential donors *Human Reproduction*. 18 (4): 871-877.

McMahon, C. & Saunders, D. (2007). Attitudes of couples with stored frozen embryos toward conditional embryo donation . *Fertility and Sterility.* 91: 140-147.

Melbourne IVF (MIVF) (2004). *Personal impacts*. Retrieved 27 Jan 2004 from http://www.mivf.com.au/personal/personal_c.asp.

Mendel, I. (2007). Knowledge / power / empowerment: Feminism and the politics of epistemology. University of Vienna, Austria. Paper presented in June 2007, Umea, Sweden. Retrieved 7 Dec 2007 from http://www.umu.se/kvf/aktuellt/ppf/imendel.pdf.

Metherell, M. (2005, 25 April). IVF users deny hike is behind blow-out in. *Sydney Morning Herald*.

Miller, T. (2007). *Making babies: Personal IVF stories*. Melbourne, Scribe Publications.

Min, J., Breheny, S., MacLachlan, V. & Healy, D. (2004).What is the most relevant standard of success in assisted reproduction? The singleton, term gestation, live birth rate per cycle initiated: the BESST endpoint for assisted reproduction. *Human Reproduction*. 19(1): 3-7.

Molloy, D., Hall, B., Ilbery, M., Irving, J. and Harrison, K. (2009). Oocyte freezing: timely reproductive insurance? *Medical Journal of Australia.* 190 (5): 247-249.

Mori, M. (2008). Secular perspectives on twenty-first century ethics in human rights: Why religious views and attitudes are becoming obsolete and possibly dangerous. *Ethics, Bioscience and Life.* 17(3). Retrieved 7 Nov 2008 from http://www.RBMonline.com.

Morse, J. (Ed). (1994). *Critical issues in qualitative research methods*. London, Sage.

Murdoch, A. (1985). When IVF is a lost labour. *The Age*, 10/4/85. In *Reproductive technology: Selected articles reprinted from The Age March 1985 – October 1987*. Reprint booklet number 50.

Mykituik, R. & Nisker, J. (2007). Determinants of embryo 'health': Are there implications for children? Conference paper presented at the *Nobody's child, everybody's children conference,* Malaspina University College, May 24-26, 2007. Retrieved 22 Oct 2008 from http:// www.mala.ca.

Napier, L. (1989). The barren desert flourishes in many ways: From infertility to in-fertility. In Klein, R. (Ed). *Infertility: Women Speak out.* Sydney, Pandora.

National Health and Medical Research Council (NHMRC) (2004). *Ethical guidelines on the use of reproductive technology in clinical practice and research.* Canberra, Australian Government Printing Service.

(1998).*The long-term effects on women from assisted conception. Canberra,* Australian Government Printing Service.

New South Wales Department of Health (1997). *Review of the Human Tissue Act 1983: Discussion paper on assisted reproductive technology.* Retrieved 20 Nov 2002 from http://www.nsw.gov.au/csd/llsb/legislation/humantiss.html.

Newton, C., Fisher, J., Feyles, F., Tekpetey, F., Hughes, L & Isacsson, D. (2007). Changes in patient preferences in the disposal of cryopreserved embryos. *Human Reproduction.* 22(12):3124-3128.

Nikolaos, M. (2008). The Greek Orthodox position on the ethics of assisted reproduction. *Ethics, Bioscience and Life.* 17(3). Retrieved 7 Nov 2008 from http://www.RBMonline.com.

Nordqvist, P. (2008). Feminist heterosexual imaginaries of reproduction: Lesbian conception in feminist studies of reproductive technologies. *Feminist Theory.* 9(3):273-292.

Nugent-Smith, C. & Nugent-Smith, J. (1985). *A baby maybe.* Melbourne, Oaks.

Olivennes, F. & Frydman, R., (1998). Friendly IVF: The way of the future? *Human Reproduction*. 13(5):1121-1124.

References

Olivius, C., Friden, B., Borg, G. & Bergh, C. (2004). Why do couples discontinue in vitro fertilisation treatment? A cohort study. *Fertility and Sterility.* 81:258-261.

Osburn, L. (2007). Counselling in human reproductive technologies: Diversity and rights. *International Journal of Diversity in Organisations, Communities and Nations.* 6(6): 83-91.

Palmer, T. (2004). 'Infertility is not rare'. *Health Matters*. ABC Online. Retrieved 15 Nov 2004 from http://www.abc.net.au.

Peddie, V., van Teijlingen, E., & Bhattacharya, S. (2005). A qualitative study of women's decision-making at the end of IVF treatment. *Human Reproduction,* 20(7): 1944-1951.

Pennings, G., & Ombelet, W. (2007). Coming soon to your clinic: Patient friendly ART. *Human Reproduction.* 22(8):2075-2079.

Peterson, B., Newton, C., Rosen, K. & Skaggs, G. (2006). Gender differences in how men and women who are referred for IVF cope with infertility stress. *Human Reproduction.* 21(9):2443-2449.

Pini, B. (2004). On being a nice country girl and an academic feminist: Using reflexivity in rural social research. *Journal of Rural Studies*. 20(2):169-179.

Porter, M. & Bhattacharya, S. (2008). Helping themselves to get pregnant: A qualitative longitudinal study on the information-seeking behaviour of infertile couples. *Human Reproduction.* 23(3):567-572.

Purdy, L. (2000). Empowerment or danger? *Forum for Applied Research and Public Policy,* 15(1):59-64.

Qu, L. & Weston, R. (2005). Assisted reproductive technology (ART) The fallback option? Paper presented at the *Australian Social Policy Conference, Australian Institute of Family Studies,* Sydney, 20-22 July 2005.

Quine, S., Bernard, D., Booth, M., Kang, M., Usherwood, T., Alperstein, G. & Bennett, D. (2003). Health and access issues among Australian adolescents: A rural-urban comparison. *International Electronic Journal of Rural and Remote Health Research., Education, Practice and Policy.* 3 (245). Retrieved 11 March 2009 from http://www.rrh.org.au/publishedarticles/article_print_245.pdf.

Qureshi, N., Walker, S., Pike, D. & Murray, A. (1997). Transport in vitro fertilization: Three years experience at a district general hospital. *Journal of Obstetrics and Gynaecology.* 17(5):457-460.

Rajkhowa, M., McConnell, A. & Thomas, G. (2006). Reasons for discontinuation of IVF treatment: A questionnaire study. *Human Reproduction.* 21(2):358-363.

Rapp, R. (1988). Moral pioneers: Women, men and fetuses on a frontier of reproductive technology. In Hoffman Baruch, E., D'Adamo, A. Seager, J. (Eds). *Embryos, ethics, and women's rights.* Haworth, London.

Rapp, R. (1999). *Testing women, testing the fetus: The social impact of amniocentesis in America.* London, Routledge.

Rapp, R. (2001). Gender, body, biomedicine: How some feminist concerns dragged reproduction to the centre of social theory. *Medical Anthropology Quarterly*. 15(4): 466 – 427.

Rapp, R. (2004). New technologies: The impact on women and society. Conference paper presented at *Reproductive Health in the 21st Century.* Harvard University, October 14-15, 2004.

Raymond, J. (1993). *Women as wombs: Reproductive technologies and the battle for women's freedom.* San Francisco, Harper.

Reed, S. (2001). Medical and psychological aspects of infertility and assisted reproductive technology for the primary caregiver. *Military Medicine,* 166(11): 1018.

Redshaw, M., Hockley, C. & Davidson, L. (2007). A qualitative study of the experience and treatment for infertility among women who successfully became pregnant. *Human Reproduction.* 22(1):295-304.

Reid, C. (2004). Advancing women's social justice agendas: A feminist action research framework. International Journal of Qualitative Methods. 3(3). Article 1. Retrieved 13 Sept 2005 from http://www.ualberta.ca/~iiqm/backissues/3_3/html/reid.html.

Research Centre for Reproductive Health (RCRH) (2007). *Research Impact: Solving challenges in reproductive health,* University of Adelaide. Retrieved 23 Oct 2008 from http://www.adelaide.edu.au.

Richards, L. (2005). *Handling qualitative data: A practical guide.* London, Sage.

Roach-Anleu, S. (1999). *Deviance, conformity and control*. Frenchs Forest, Longman.

Roberts, D. (2004). Poor black women and reproductive punishment. Conference paper presented at *Reproductive Health in the 21st Century.* Harvard University, October 14-15, 2004.

Roest, J., Verhoeff, A., van Lent, M., Huisman, G. & Zeilmaker, G. (1995). Infertility: Results of decentralized in-vitro fertilization treatment with transport and satellite clinics. *Human Reproduction*. 10 (3):563-567.

Rowland, R. (1988). Maternity in the laboratory: An international forum on the new reproductive technologies. *Reproduction and Genetic Engineering.* 1(2):213-214.

Rowland, R. (1992). *Living laboratories: Women and reproductive technologies.* Sydney, Sun.

References

Rushing, B. (2000). Review of Clarke, A. 1998. *Disciplining reproduction: Modernity, American life sciences and the problems of sex*. Berkeley: University of California. In *Gender and Society,* 14(1):212.

Rutnam, R. (1991). IVF in Australia: Towards a feminist technology assessment. *Issues in reproductive and genetic engineering.* 4(2):93-107.

Sachs, C. (1996). *Gendered fields: Rural women, agriculture and environment*. Boulder, Westview Press.

Salleh, A. (2008). Expert calls for vigilance on IVF problems. *ABC online*. Retrieved 20 June 2008 from Http://www.abc.net.au.

Sandelowski, M. (1990). Failures of volition: Female agency and infertility in historical perspective. *Signs.* 15:475-499.

Savulescu, J. (1999). Reproductive technology, efficiency and equality. *Medical Journal of Australia. 171*:668-670.

Schmidt, L., Holstein, B., Christensen, U. & Boivin, J. (2005). Communication and coping as predictors of fertility problem stress: Cohort study of 816 participants who did not achieve a delivery after 12 months of fertility treatment. *Human Reproduction*. 20(11):3248-3256.

Seguin, E. (2001). Narration and legitimation: The case of in vitro fertilisation. *Discourse and Society. 12*(2):195-215.

Selis, A. (1999). Liberating reproduction from despair. *Tikkun,* 14(3):31-34.

Serour, G. (2008). Islamic perspectives on human reproduction. *Ethics, Bioscience and Life.* 17(3). Retrieved 7 Nov 2008 from http://www.RBMonline.com.

Sharp, l. (2000). The commoditisation of the body and its parts. *Annual Review of Anthropology.* 29: 287-328.

Shanner, L. (1996). 'Bioethics through the back door: Phenomenology, narratives and insights into infertility'. In Sumner, W. & Boyle, J. (Eds). *Philosophical perspectives on bioethics.* Toronto, University of Toronto Press.

Shannon, T. (1988). In vitro fertilisation: Ethical issues. In Hoffman Baruch, E., D'Adamo, A. Seager, J. (Eds). *Embryos, ethics and women's rights: Exploring the new reproductive technologies.* London, Haworth.

Shenfield, F. & Sureau, C. (2002). *Ethical dilemmas in reproduction.* London, Parthenon.

Sherwin, S. (2007). Nobody's mother: The ethics of research on hhuman embryos. Conference paper presented at the *Nobody's child, everybody's children* conference, Malaspina University College, May 24-26, 2007. Retrieved 22 Oct 2008 from http:// www.mala.ca.

Shildrick, M. (1997). *Leaky bodies & boundaries: Feminism, postmodernism and (bio)ethics.* London*,* Routledge.

References

Shildrick, M. (2002). *Embodying the monster: Encounters with the vulnerable self*. London, Sage.

Shildrick, M. (2004). Genetics, normativity, and ethics: Some bioethical concerns. *Feminist Theory.* 5(2):149-165.

Shildrick, M. (2006). Monstrous reflections on the mirror of the self-same. In Orr, D., Lopez-McAlister, L., & Kahl, E. (Eds) *Belief, bodies and being*: *Feminist reflections on embodiment.* Lanham, Rowman & Littlefield.

Sinclair, J. (2003, 20 July). One in a million. *The Sunday Age*.

Skatssoon, J. (2005). End of embryo ban a boon for scientists. *News in Science – ABC online*. Retrieved 19 April 2005 from http://www.abc.net.au.

Slade, P., O'Neill, C., Simpson, A. & Lashen, H. (2007). The relationship between perceived stigma, disclosure patterns, support and distress in new attendees at an infertility clinic. *Human Reproduction.* 22(8):2309-2317.

Smeenk, J., Verhaak, C., Eugster, A., Van Minnen, A., Zielhuis, G. & Braat, D. (2001). The effect of anxiety and depression on the outcome of in-vitro fertilisation. *Human Reproduction.* 16(7):1420-1423.

Smith, J. (2003). 'Suitable mothers': Lesbian and single women and the 'unborn' in Australian parliamentary discourse. *Critical Social Policy*. 23(1):63-88.

Smith, J. (2006). Medicare and assisted reproductive technologies. Australian Health Policy Institute Policy Briefing Paper #1, May 2006. Retrieved 13 June 2008 from http://www.ahpi.health.usyd.edu.au/research/publish/ivfbrief.pdf.

Sprague, J. (2005). *Feminist methodologies for critical researchers: Bridging differences.* Walnut Creek, Altamira.

Strier, R. (2006). Anti-oppressive research in social work: A preliminary definition. *British Journal of Social Work.* 37(5):857.

Szoke, H. (2003). Australia – a federated structure of statutory regulation of ART. In Gunning, J. & Szoke, H. (Eds). *The regulation of assisted reproductive technology.* Aldershot, Ashgate Publishing.

Thomas, A. (2003). UK expert raises IVF alarm. ABC online, News on Science. Retrieved 15 Nov 2004 from Http://www.abc.net.at.

Thompson, J., Lind, K., Roberts, C., Robertson, S & Robinson, J. (2002). Epigenetic risks related to assisted reproductive technologies. *Human Reproduction.* 17 (11):2783.

Thompson, C. (2005). *Making parents: The ontological choreography of reproductive technologies.* Cambridge, MIT Press.

Thorne, S., Reimer Kirkham, S., & O'Flynn-Magee, K. (2004). The analytic challenge in interpretive description. *International Journal of Qualitative Methods*. 3(1).

Article 1. Retrieved 19 August 2008 from
http://www.ualberta.ca/~iiqm/bacjissues/3_1/pdf/thorneetal.pdf

Throsby, K. (2004). *When IVF fails: Feminism, infertility and the negotiation of normality.* Basingstoke, Palgrave Macmillan.

Trounson, A. (1999). What if there is a 'sunset clause' on the Y chromosome? *Medical Journal of Australia.* 171:660-662.

Tunick, B. (1999). What you should know about assisted reproductive technology. *Female Patient,* 24(9): 53-55.

Valentine, K. (2008). After antagonism: Feminist theory and science. *Feminist Theory.* 9(3):355-365.

Van Empel, I., Nelen, W., Hermens, R. & Kremer, J. (2008). Coming soon to your clinic: High quality ART. *Human Reproduction.* 23(6):1242-1245.

Verhaak, C., Smeenk, J., Nahuis, M., Kremer, J. & Braat, D. (2007). Long-term psychological adjustment to IVF/ICSII treatment in women. *Human Reproduction.* 22(1):305-308.

Waite, K. & Harrison, R. (2004). From egg to offspring. Survival rates in IVF: Where does it all go wrong? *Irish Medical Journal.* Retrieved 15 Oct 2008 from http:// www.imj.ie.

Waller, L. (1983). *Report on donor gametes in IVF.* Victorian Government Committee to consider the social, ethical and legal issues arising from IVF. Melbourne.

Waller, L. (2003). 'Development and regulation of assisted reproduction: A world view of early days'. In Gunning, J. & Szoke, H. (Eds). *The regulation of assisted reproductive technology.* Aldershot, Ashgate Publishing.

Wang, Y., Dean, J., Badgery-Parker, T., Sullivan, E. (2008). *Assisted reproduction technology in Australia and New Zealand 2006.* Assisted Reproduction Series no. 12. AIHW cat. No. PER43.Sydney. AIHW National Perinatal Statistics Unit.

Wang, Y., Sullivan, E., Healy, D. & Black, D. (2009). Perinatal outcomes after assisted reproductive technology treatment in Australia and New Zealand: Single versus double embryo transfer. *Medical Journal of Australia.* 190(5):234-237.

Webster, A. (2002a). Innovative health technologies and the social: Redefining health, medicine and the body. *Current Sociology.* 50(3):443-457.

Webster, F. (2002b). Do bodies matter? Sex, gender and politics. *Australian Feminist Studies.* 17(38):191-205.

Wendt, S. & Boylan, J. (2008). Feminist social work research engaging with poststructural ideas. *International Social Work* 51(5): 599-609. Retrieved 19/08/08 from http://www.isw.sagepub.com.

Wiczyk, H. (2000). Infertility: A modern work-up. *Female Patient,* 25(8): 72

Williams, R. (2008, 11 August). Lots of life in IVF market. *The Age.*

Winston, R. (2007). *A child against all odds*. London, Bantam.

Wirtberg, I., Moller, A., Hogstrom, L., Tronstad, S. & Lalos, A. (2007). Life 20 years after unsuccessful infertility treatment. *Human Reproduction.* 22(2):598-604.

Wood, C. & Gordon, S. (2001). Defining moments in medicine. *Medical Journal of Australia* 174:13-14. Retrieved 27 Nov 2003 from http://www.mja.com.au.

Wroe, D. (2005, 21 April). Medicare cuts to hit couples using IVF. *The Age*.

Yamin, A. (1997). Transformative combinations: Women's health and human rights. *Journal of the American Medical Women's Association. 52*(4):169-173.
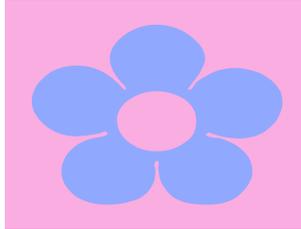
Appendices

Appendix one

Recruiting Participants

School of Humanities and Social Sciences, Charles Sturt University

Are you a woman who has used

IVF?

I am researching my thesis on women's experiences of IVF and I'm keen to talk to a range of women - whether or not IVF has been successful/unsuccessful, any age group, whether you are still using IVF or have discontinued.

Please contact me to arrange a confidential interview at a time and place suitable to you.

Your help would be greatly valued.

Please phone or leave a message 02 69332179 / kbell@csu.edu.au
(Karen, at Charles Sturt University).

> **NOTE: Charles Sturt University's Ethics in Human Research Committee has approved this project. If you have any complaints or reservations about the ethical conduct of this project, you may contact the Committee through the Executive Officer:**
>
> **Ethics in Human Research Committee,   The   Grange,   Charles   Sturt University**
>
> **Bathurst NSW 2795. Tel: (02) 6338 4628. Fax: (02) 6338 4194.**
>
> Any issues you raise will be treated in confidence and investigated fully and you will be informed of the outcome.

Information Form

Charles Sturt University, School of Humanities and Social Sciences

RESEARCH PROJECT: The experiences and support needs of women using assisted reproduction clinics in non-metropolitan locations.

RESEARCHER: Karen Bell

We hear a lot in the media about IVF but we often don't hear a lot from the women who have experienced what it's like to go through this sort of treatment. We hear even less from women who are living outside of major cities and towns, so we often don't get any information on what it's like for these women to access IVF treatment. Given that IVF treatment can be financially and emotionally costly, it is important to hear more from the women who have experienced IVF treatment so that they can express their needs and their actual experiences.

This research aims to explore women's support needs during the time they were clients of an IVF clinic.

In particular, the researcher hopes to explore how women living outside of metropolitan areas experience IVF treatment and whether support services were accessible and appropriate for them.

The main sources of information for the project are women from regional and rural areas who have volunteered to participate in an interview with the researcher. The researcher will also use information brochures from IVF clinics and information from IVF clinics' websites to determine the nature of the support services available to clients.

At no time will information be sought from clinics about individual clients. All information from the research interviews will be kept confidential. Only non-identifying information will be used for the research report.

Interviews are expected to take between one and two hours to complete. Participants can withdraw at any stage of the research. Any issues you raise will be treated in confidence and investigated fully and you will be informed of the outcome.

> NOTE: Charles Sturt University's Ethics in Human Research Committee has approved this project. If you have any complaints or reservations about the ethical conduct of this project, you may contact the Committee through the Executive Officer:
>
> The Executive Officer
>
> Ethics in Human Research Committee
>
> The Grange
>
> Charles Sturt University
>
> Bathurst NSW 2795   Tel: (02) 6338 4628   Fax: (02) 6338 4194

Thank you for taking the time to read this information sheet. Please contact me if you would like to volunteer to be interviewed. Your contribution to this research would be

highly valued and much appreciated. We can then make suitable arrangements for an interview time.
Karen Bell, Charles Sturt University. Ph.02 69332179 / kbell@csu.edu.au

Consent Form

Charles Sturt University

School of Humanities and Social Sciences

Research project: The experiences and support needs of women using assisted reproduction clinics in non-metropolitan locations
Researcher: Karen Bell, Charles Sturt University Boorooma St Wagga,
ph 69332179

I, ---(print name and date of birth), of ---------------------
--(print address), have volunteered to participate in an interview with Karen Bell for her Doctor of Philosophy degree research project on women's experiences and support needs during treatment at assisted reproduction clinics. I have been advised of the purpose of the research.

I understand that any information or personal details gathered in the course of this research about me are confidential and that neither my name nor any other identifying information will be used or published without my written permission.

I can withdraw from this research at any stage and that I need to inform Ms Bell of any decision I make to withdraw from the research as soon as possible after that decision.

I understand that all records of the research will be kept in a locked filing cabinet in the School of Humanities and Social Sciences for at least five years and that only the researcher has access to the records in this time. Once this time has passed, the records will be shredded and disposed of.

The purpose of the research has been explained to me and I have read and understood the information sheet given to me.

The purpose of the research has been explained to me, including the (potential) risks/discomforts associated with the research. (I have read and understood the written explanation given to me). I have received a card with information on sources of supportive counselling, should I require supportive counselling and understand that I am responsible for organising this follow-up if needed. This card also contains information on the complaint procedure.

Charles Sturt University's Ethics in Human Research Committee has approved this study.

I understand that if I have any complaints or concerns about this research I can contact:

Executive Officer, Ethics in Human Research Committee

The Grange Charles Sturt University Bathurst NSW 2795 Phone:(02) 6338 4628

Signed_____Date_____

Letter to AR service providers

Dear ……………….

I am conducting PhD research into the experiences of women who have been treated at assisted reproductive technology (IVF) clinics. I am particularly interested in the experiences of women living outside major metropolitan areas and how they have accessed the supportive counselling offered by IVF clinics.

I would very much appreciate it if you could display the enclosed notice in your waiting room, so that potential interviewees can make contact with me to volunteer to participate in this research.

I have also enclosed a general information sheet about the research for your perusal. Please contact me if you would like further information on this project.

Your help in this matter would be valuable to the project.

NOTE: Charles Sturt University's Ethics in Human Research Committee has approved this project. If you have any complaints or reservations about the ethical conduct of this project, you may contact the Committee through the Executive Officer:

The Executive Officer

Ethics in Human Research Committee

The Grange

Charles Sturt University

Bathurst NSW 2795

Tel: (02) 6338 4628

Fax: (02) 6338 4194

Any issues you raise will be treated in confidence and investigated fully and you will be informed of the outcome.

Yours faithfully,

Karen Bell, BA, BSW, PhD candidate
School of Humanities and Social Sciences
Charles Sturt University Ph. 02 69332179 / kbell@csu.edu.au

Appendix two

Interview schedule – p.1

- Introductions

- Outline purpose of research

- Confidentiality

- Read through consent form, obtain signature

- Demographic details – age range, family situation, location / isolation

- Establish nature of involvement with IVF – When ? Where? Current? Outcome? Duration?

- Experiences of IVF - at different stages (early, middle, ending phases of 'treatment')
- Preparation – self, partner, family

- Benefits / Costs – emotional, financial, travel, etc

- Support – Was a counsellor seen? What was this like? Did it meet your needs? If yes, in what ways, if not, what would have been helpful?
- other supports – groups? Newsletters? Online chats?
- Informal support – family? Friends? Community?
- *(Give counselling card to participant)*

- What would you say to someone contemplating IVF?

- Any suggestions / recommendations for changes to how IVF services are delivered?

- Other comment?

- Conclude – summarise, clarify, re-state aims of research and thank for participation

Interview schedule – p.2 - Demographic details

	Details	Other notes
Age		
Family		
Children - *note natural / assisted conception*		
Location / distance to clinic(s)		
Income level		
Ethnicity		
Employment		
Religious affiliation / spirituality		

- Conclude interview – summarise, clarify, re-state aims. THANK.

- Ensure SUPPORT SERVICES CARD given to participant.

Support services card -

Women's Health Centre - Street address, Town. ph. …………….

Community Health Centre – Street address, Town. ph………………

ACCESS – 1800 888896 / www.access.org.au

Letter to participants

December 2006

Dear

In 2005 you were kind enough to participate in an interview with me about your experiences of IVF. I would like to thank you most sincerely for taking the time to speak with me and making such a worthwhile contribution to this research into women's experiences and support needs in relation to IVF.

When we met, I indicated that I hoped to send all research participants a broad summary of interviewees' responses before the end of 2005. At the time, I thought that timeframe was realistic; however as we approach the end of *2006*, the timeframe it seems was not generous enough! Other work demands have meant that the lengthy process of transcribing interviews and the preliminary analysis of interview information was delayed.

Please find enclosed the summary of the interviews and please note that it is very general and that no identifying information has been included.

The full research report (PhD thesis) is scheduled for completion by the end of 2008 / early 2009.

Again, many thanks for your participation. I hope that all is well and that you enjoy the festive season.

Yours sincerely,

Karen Bell

CSU PhD student / lecturer.

General summary of research participants' responses

The nature of involvement with assisted reproduction (AR)

- Interviewees had experienced a range of AR procedures including ovarian stimulation, artificial insemination by partner/ by donor, donor ova conception, IVF, ICSI, and to a lesser extent – GIFT.

- A minority of women had conceived a successful pregnancy on the first attempt, but most had several attempts over several years before discontinuing AR – either because of a successful outcome or because 'it was just time to stop'.

- Most women had used clinics in non-metropolitan locations within 30 minutes travel time from home. Some had travelled considerable distances from their home to access an AR clinic.

- Where there was a clinic located in their nearest regional centre, most women chose to use it. A few women chose to use a metropolitan clinic despite significant travel / cost. Often this was due to dissatisfaction with the local clinic. There were various reasons for the 'dissatisfaction' but the most common one was that the local clinic did not offer a full range of AR services – particularly pre-implantation screening / genetic counselling, etc.

- There was a fairly even spread of women who had accessed a fully independent, full-time accessible, regionally based clinic and those who had accessed an intermittently accessible, 'satellite' clinic (with a 'parent' clinic in a major city). The 'satellite' clinics were generally only accessible every 3 months and had limited locally-based staff and mostly relied on consultant medical staff visiting from the city-based 'parent' clinic for the quarterly clinics.

Outcomes

- There was a fairly even spread of women who'd had success with AR (1 or more children born as a result) and women who had not had a successful AR outcome. Some of the women who hadn't had success with AR, had subsequently conceived children without further assistance and some had children prior to needing AR. A slightly smaller number of interviewees remained involuntarily childless and at the time of interview, were still using AR.

- Of women who'd had children after AR procedures, there was a higher rate of multiple births relative to non-AR births.

- Expectations re AR / knowledge prior to becoming a client

- Most women said that they initially expected much higher success rates than the actual success rates

- Most had at least a general understanding of IVF and broadly what it involved. Many however said that they did not realise exactly how much AR would impact on their lives.

- Quite a few women attributed the lack of success with AR to their own body rather than to the technology itself.

Experiences of AR procedures

- Approximately half of the responses were that procedures were carried out with sensitivity and professionalism. Many of these respondents reinforced the importance of good preparation for procedures, clear expectations, professional behaviour by all staff (medical, nursing, reception/admin), courtesy and respect from all staff.

- However, other women told of less satisfactory experiences, including a lack of privacy, lack of introductions to staff, unknown people with unknown purpose/role being present for procedures, lack of confidentiality in smaller towns/cities, feeling like 'a herd of cattle', lack of adequate waiting rooms and post-procedure recovery rooms, inappropriate comments by staff, unprofessional receptionists. For some women, they felt they had been treated in an undignified manner and this added to feelings of vulnerability and discomfort.

- The perception of how painful procedures were varied for individual women, as you would expect. Many said that the injections were the most disliked procedure of treatment cycles and that waiting for results of each cycle was one of the worst aspects, emotionally.

- Almost all said they were very thankful for the existence of AR as an option and for the opportunity to try it, even when it hadn't been successful.

Impacts – financial, emotional, spiritual, relationships, travel, work, etc

- Almost without exception, the various impacts of AR were considerable. Most had re-prioritised major financial commitments like buying a home or travel (etc) to fund AR. Most mentioned that rebates now available from Medicare were a huge help. Many mentioned that if the local clinic not existed, that it would not be possible to accommodate the extra travel, financial (etc) impacts of accessing AR.

- Quite a few mentioned the importance of flexible work arrangements.

- The phrase 'emotional rollercoaster' was often used to describe the emotional impacts of AR.

Support – formal (counsellor, group, online), informal (partner, family, friends, community, etc)

- Most had not had ongoing counselling support from a clinic-employed counsellor. The majority had a one-off session with a counsellor. Most did not feel that they had a choice but to have one session and many said that they did not find this session useful. Quite a few also said that the purpose of the session was not made clear enough and some had been concerned at the time that they were being assessed and judged.

- There were significant variations in the accessibility of ongoing counselling. Some were not made aware that they could see a counsellor on an ongoing basis and many said that they would have appreciated some further follow-up from a counsellor, particularly when procedures had been unsuccessful or during the waiting time.

- Most women sought and received varying levels of support from their partners, family and friends.

- Some had the opportunity of attending support and information groups. The women who'd had the opportunity to be part of an information/education group spoke very highly of this and as a spin-off they had met other couples using AR with whom they built mutually supportive relationships.

- The support of someone else who'd been through AR was highly valued.

- Quite a few mentioned that support groups weren't attractive to them and that they were concerned about their privacy and/or that they perceived that these groups could develop a negative 'tone' and that they would therefore be unhelpful. The women who said this also preferred that support groups be facilitated by an experienced coordinator.

- The women who'd been part of successful support groups said that they had formed lasting bonds with some group members and that it was a very positive source of support.

- The support of the clinic for groups was identified as important.

- Online information was important for a lot of women. Many had accessed online 'diaries' of other women's experiences, some had used chat rooms, some had observed, but not actively used chat rooms, forums, etc.

- Newsletters were identified as useful and informative.

Perception of self

- Approximately half said that their thinking about themselves and levels of self-confidence and esteem had changed as a result of experiencing involuntary childlessness. For others this was not a major issue and their sense of self remained essentially the same. Where there was a clear explanation for the period of infertility, self esteem seems to have been easier to maintain.

Ideals/ beliefs about motherhood

- Many women spoke of the shock of experiencing fertility challenges and of feeling powerless / lacking control over an aspect of life valued as important.

- Most, though by no means all, said that they had always imagined they'd have children when they were ready and that when this did not happen as easily as assumed, this was a major life crisis. Quite a few added to this by saying that once conceiving a child was found to be problematic, that the desire and determination to conceive became even stronger.

Recommendations to clinics – positive, negative

- Communication was a key issue in what makes a clinic experience positive or negative. Good, clear, consistent and accessible information from medical, nursing and support staff was repeatedly identified as essential to a positive experience.

- Many women said that having one or two contact people would have been more helpful than having to deal with a larger number of different staff – some of whom might not know your situation / stage / background, etc.

- A comfortable environment – waiting areas and procedure rooms

- Good reception staff

- An overall feeling of being an individual, rather than 'just another customer'

- Many said that procedures need to be carried out with respect and sensitivity and that staff should always be mindful of the importance of what they were doing – that AR is not like other 'medical' procedures.

- Some had positive experiences where embryo transfers were done in darkened rooms with candles / music / etc. Most found this very positive and caring.

- Many mentioned a need for more information on all aspects of AR and that the information needed to be in plain English with accurate, honest, factual information on which to base informed decisions.

- Quite a few specifically mentioned the need for better information on embryo storage – the costs, timeframes, options, etc.

- Many said that partners needed more acknowledgement, inclusion and support during AR.

Advice to someone contemplating AR

- 'Get as much information, from as many sources as you can'

- be prepared for the significant financial impact

- 'be prepared for it to take over your life' / 'don't let it take over your life – maintain other activities as much as you can'

- try to make sure your relationship with your partner is as strong as it can be

- other comments included - 'be determined', 'don't give up', 'ask lots of questions', 'take care of yourself', 'know when enough is enough'

Motivations to participate in this research

- 'To help other women' was the most common motivation

- A considerable number also said that the general public and health professionals need more information, directly from women, about what it is like to be involuntarily childless and what AR is actually like.

- A few other women said that being interviewed was a way of regaining some sense of control over an essentially 'uncontrollable' experience.

- Some others said that doing the interview was one way of 'properly ending' a chapter in the story of their life. For a small number of interviewees this was compounded by the fact that they had chosen not to tell very many people of their AR experiences and that speaking with an unknown person was one way of transferring this information.

- A few women said that they had done research themselves and understood how difficult it can be sometimes to find interviewees.

- Most women found out about the research via advertisements in their local newspaper, some from notices in health centres and some from information given to them by women's health workers.

Appendix three

Initial topic codes

Clinic staff	Male doctor	Clinic mistake	Woman's body
Clinic information	Advice to others	Access	Biomedical focus
Foetal reduction	Options/control	AR involvement	Limits on AR
Physical impact	Self – impact	Work – impact	Emotional – impact
Travel – impact	Financial – impact	Relationship – impact	Lifestyle – impact
Waiting	Future IVF	Infertility reason	Secrecy / privacy
Injections	Involuntary childlessness	Support needs	Support sources
Support group	Support counselling	Preparation	Success rates information
Other women at clinic	Attitude to infertility	Continuing AR	Pre-AR
Public/private	Knowledge AR	Unsuccessful AR	Decision to stop
Natural success	Adoption	Genetic parenthood	Religion/spirituality
Assume woman infertile	Advice to clinic	Media reporting	Men's needs
Self-blame	Donating sperm	Other AR	Time on AR
Impact – dignity	Impact – rural	Impact – other childless women	Impact – other women as mothers
Impact – involuntary childlessness	Pregnancy – interventions	Pregnancy loss	Pregnancy complications
Birth complications	Neo-natal	Motivation to participate in research	Support – online
Agency	Expectations	Male infertility	Surplus embryos
General practitioner information on infertility	Frame of mind	AR hope	Successful AR
Motherhood	Experience of AR	Perceptions of AR	Reactions to AR
Alternatives tried	Opinions	Pronatalism	Number of attempts

Thematic codes used in NVivo (and codes collapsed to this theme)

Access – *(GP information)*	**Advice to others**	**Advice to clinic**	**Alternative therapies** – *(alternatives tried)*
AR- *(perceptions, preparation, pre-AR, involvement, experience, waiting, time on AR, number of attempts, reactions, future AR, knowledge of AR, success rates, unsuccessful AR, hope)*	**Clinic** – *(staff, information, male doctor, mistakes, biomedical focus, public/private, mistake)*	**Control** – *(options, agency)*	**Discontinuing** – *(decision to stop, limits, future, continuing)*
Embryo – *(surplus embryos, foetal reduction)*	**Expectations re success** – *(expectations)*	**Impacts** – *(financial, emotional, relationship, physical, self, work, travel, lifestyle, dignity)*	**Infertility reasons** – *attitude, assumption of female infertility, male infertility, GP information on infertility)*
Information	**Injections**	**Involuntary childlessness** – *(experience, self-blame, pronatalism, adoption)*	**Man** – *(donating sperm, needs, infertility, donor sperm)*
Media	**Motherhood** – *(impact- other women as mothers)*	**Motivation to participate**	**Natural success** – *(genetic parenthood)*
Opinions – *(other AR)*	**Others' reactions**	**Outcomes** – *(successful AR, unsuccessful AR, pregnancy loss, birth / complications)*	**Postnatal** – *(neo-natal)*
Pregnancy – *(complications, interventions, loss)*	**Privacy** – *(secrecy)*	**Rural health** – *(impacts – rural)*	**Spirituality**
Support – *(needs, sources, group, counselling, online)*	**Woman** – *(agency, other clinic women, self, body, impact – other childless women, frame of mind)*		