



**THE UNIVERSITY OF QUEENSLAND**  
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**Expectations and experiences of midlife intending mothers engaging  
with Assisted Reproductive Technology**

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## Abstract

The age for optimal women's childbearing, with the best chance of delivering a healthy baby, is generally considered to be when aged in their 20s years. Some researchers propose that fertility declines occurs from 32 years of age. After this age women have a decreasing chance of conception attributed primarily to age-related chromosomal changes in their oocytes. Midlife intending mothers (women aged 35 and older) are the largest users of Assisted Reproductive Technology (ART) in Australia. Whatever the aetiology of infertility, age-related changes in their oocytes increase the chance of spontaneous miscarriage and decrease the chance of a live healthy baby. In 2013 the overall live birth rate per initiated ART cycle for Australian women of all ages was 18.2%. A breakdown into age groups shows per initiated cycle for those aged; 35–39 years was 16.3%, 40–44 years 5.9%, and 45 years or older 1.2%. Women unaware of this low success rate of ART may experience involuntary childlessness.

This research investigates perceptions of women's fertility decline and ART success from a group of women who had used ART, and from men and women in the community who may not have used ART. Women who had used ART and a community cohort were surveyed. Responses from these two groups were analysed separately and compared. Women who had used ART were asked about their experiences at their clinic, and if treatment had social or psychological repercussions. Participants asked about their perceptions of media portrayal of ART success for women aged 35 and older. The concept that ART has become commodified, where commodification is the transformation of services or entities into a commodity, is explored. Those who had used ART suggested recommendations for younger women about childbearing.

A mixed-methods approach was utilised. Data were gathered from three cohorts of participants. Quantitative and qualitative data were gathered from an in-vitro fertilisation (IVF) support group (N = 68) and qualitative data from an interview group of IVF users (N=6) who had engaged with ART treatment either currently or recently. Some had conceived and some were still having treatment. The community group (N= 1243) comprised men and women over 18 years of age who participated in a Queensland-wide telephone survey. Quantitative data gathered from the support group and the community were analysed using SPSS. Qualitative data were explored via thematic analysis.

Thematic findings from the interview group supported findings of the support group. Most women knew the benefits and risks of delaying childbearing and made an informed choice

to use ART. Most were aware that fertility declined from the age of 35, yet this age group is the major consumer of ART. Most women younger than 40 years believed they would get pregnant and have a healthy baby. Only half of the women aged 40 years and older had that confidence. However, this insight may have been gained after using ART. Women found their experience physiologically and psychologically challenging and those who didn't conceive, found making the decision to stop treatment confronting. Some were confused on the published success rates, and expectations elevated from overall rather than age specific pregnancy not birth rates.

Support group and interview participants felt delayed childbearing was mainly due to lack of a relationship partner whereas community members believed career or work aspirations. Both the support group and community group agreed that women's fertility declined from the age of 35 years but significantly more community members, and significantly more men than women, thought that some women were fertile when aged in their 40s. Similarly, community members had much higher expectations that ART would achieve a pregnancy and a live birth for older women than the support group. Most participants believed media and clinic marketing portrayed ART as successful for older women and did not accurately depict the stories of many women. Some women felt that ART was commodified.

Findings highlight that women are delaying childbearing, despite some awareness that fertility declines from midlife. This knowledge was tempered by faith that ART is a successful technology. This research highlights the quandary women may experience in making decisions on timing of childbearing. Further research using a larger sample cohort would expand the findings of this study.

Public funding by Medicare for unlimited ART cycles for women aged over 40 years, or for women with little chance of success, requires review. Psychological support is needed for women who have difficulty stopping treatment.

Lack of a coherent body of knowledge on age-related infertility and success rates amongst the general public is of public health interest. Information needs to be accurate and disseminated by an independent body. Primary health providers could better inform younger women about age-related fertility decline. Overall, the message that ART is not a reliable "fall-back" option could be promoted by media and primary health providers. Accurate information on the limits of women's fertility and success rates of ART for women of all ages allows women to make informed decisions on the timing of their childbearing.

## **Declaration by author**

This thesis is composed of my original work, and contains no material previously published or written by another person except where due reference has been made in the text. I have clearly stated the contribution by others to jointly- authored works that I have included in my thesis.

I have stated the input of others to my thesis as a whole, including statistical assistance, survey design, data analysis, significant technical procedures, professional editorial advice, and any other original research work used or reported in my thesis. The content of my thesis is the result of work I have carried out since the commencement of my research higher degree candidature and does not include a substantial part of work that has been submitted to qualify for the award of any other degree or diploma in any university or other tertiary institution. I have stated which parts of my thesis, if any, have been submitted to qualify for another award.

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## 1.1

### Publications during candidature

No presentations after 2009, but presentations and publications prior to 2009 outlined in Chapter 1.

### Publications included in this thesis

Contributor	Statement of contribution

## **Contributions by others to the thesis**

An interview facilitator, as described in Chapter 5, conducted the face-to-face interviews to avoid the possibility of interviewer bias. Statistical assistance for data analysis verified the researchers findings and checked their validity. A professional editor checked the APA formatting of the final document.

## **Statement of parts of the thesis submitted to qualify for the award of another degree**

None

## Acknowledgments

When Rachel saw that she bore Jacob no children, she envied her sister. She said to Jacob, "Give me children, or I shall die" (The Holy Bible Standard English Version, 2001). This biblical passage illustrates that women over the centuries have experienced pain and emotional suffering from infertility and despite reproductive medicine, not all women will be able to have a child.

This research was initiated after working at an infertility clinic for 17 years. Within that time, I was aware of women in their midlife trying for a pregnancy. Many had minimal understanding that their fertility waned from the age of 35 years and that ART did not guarantee success. Many experienced a range of emotions from grief to elation depending on their cycle outcome. Some had many cycles of ART, however even when their chances were small, they found it difficult to stop treatment despite the emotional, physical and financial toll. I wanted to know why women found themselves in this predicament, rather than having children when younger.

I thank all the participants, particularly the women from *Friends* and Life Fertility who bared their souls to discuss their very personal ART journey. Many participants made a plea for greater public awareness of limitations of women's fertility, and I hope this can be achieved.

This research was undertaken over a number of years. During this time, I juggled research with working, bringing up a family, and building a house, which was, at times, challenging. I am grateful for the support of my husband Doug and my daughters Adriane and Verity to keep me on track during this time. I thank them for their patience and understanding.

I would also like to thank my supervisors along the way, Dr. Sandy Taylor, Dr. Janeen Baxter who encouraged me to approach the topic within a social science context. Dr. Tracey Papinczak and Dr. David King allowed me to mix social science within a medical context and shaped the direction of the research. I learnt so much from each of my supervisors who gave me so much of their time and their wise counsel. I appreciate their patience.

I dedicate this research to my late father Rudolf Gartner, an accomplished biochemist who was my inspiration for a career in science.

## **Keywords**

Delayed childbearing, age-related fertility decline, IVF, ART, commodification, medicalisation, and public health.

## **Australian and New Zealand Standard Research Classifications (ANZSRC)**

ANZSRC code: 111404, Reproduction, 60%

ANZSRC code: 111712, Health Promotion, 20%

ANZSRC code: 160508, Health Policy, 20%

## **Fields of Research (FoR) Classification**

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FoR code: 1117, Public Health and Health Services, 20%

FoR code: 1605, Policy and Administration, 20%



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## Glossary

ACCC: Australian Competition and Consumer Commission

Aetiology: The cause, set of causes, or manner of causation of a disease or condition

Aneuploidy: Refers to any number of chromosomes that is not euploid, and for constitutional chromosome disorders, usually refers to an extra copy of a single chromosome (trisomy) or absence of a single chromosome (monosomy).

ANZARD: Australian and New Zealand Assisted Reproductive Databases. An initiative of the Fertility Society of Australia (FSA) is to provide a joint data collection for both the NPESU and the Reproductive Technology Accreditation Committee (RTAC) of the FSA. The purpose of the ANZARD collection is to monitor the perinatal outcomes of assisted reproduction and to assess the effectiveness of ART treatments in Australian and New Zealand fertility clinics.

Apoptosis: Programmed cell death.

ART: Assisted Reproductive Technology ART encapsulates a range of treatments or procedures that involve the in vitro handling of human oocytes and sperm or embryos for the purposes of establishing a pregnancy. ART is non-coital, technically assisted reproduction that does not include artificial insemination.

AS: Angelmann Syndrome.

Atresia: Ovarian follicle atresia is the periodic process in which immature ovarian follicles degenerate and are subsequently re-absorbed during the follicular phase of the menstrual cycle.

Autologous cycle: An autologous cycle is an ART treatment cycle in which a woman intends to use, or uses her own oocytes.

BWS: Beckwith-Wiedemann Syndrome.

Blastocyst: An embryo comprising approximately 100 cells usually developed by the 5th or 6th day after fertilisation.

CGH: Comparative genetic hybridization is a micro-array technique that permits the detection of chromosomal copy number changes without the need to culture the cells.

Cleavage stage embryo: An embryo containing approximately 8 cells usually developed by the 2nd or 3rd day after fertilisation.

**Clinical pregnancy:** Ongoing pregnancy confirmed by elevated levels of hCG or evidence by ultrasound of one or more gestational sacs (with or without a foetal heart), or examination of the products of conception with chorionic villi present, or ectopic pregnancy diagnosed by ultrasound or definitive clinical signs of pregnancy.

**Clomiphene Citrate (Clomid/Serophene):** Stimulates the secretion of FSH and LH. Use to regulate irregular ovulation, stimulates ovulation, and increases oocyte production.

**Controlled ovarian hyperstimulation:** Pharmaceutical treatment to induce the development of multiple ovarian follicles in order to obtain multiple oocytes at oocyte pick-up (OPU).

**Cumulative pregnancy rate (CPR):** The calculation of success of a ART program where a pregnancy is achieved after one or two IVF/ICSI cycles, including the use of any "spare" frozen embryos

**Donation cycle:** ART treatment cycle in which a woman intends to donate, or donates her oocytes to others. A donation cycle may result in the donation of either oocytes or embryos to a recipient woman.

**Ectopic pregnancy:** A pregnancy in which implantation occurs outside the uterine cavity most commonly in the fallopian tube.

**Embryo:** An egg that has been fertilised by a sperm and has undergone one or more divisions.

**Embryo transfer:** The transfer of one or more embryos, selected from a larger cohort of viable embryos.

**Epigenetic:** Changes in gene expression caused by molecular mechanisms other than the mutations in the DNA sequence itself.

**Euploid:** The number of chromosomes in a normal haploid gamete.

**Fallopian tube:** One fallopian tube is attached to each ovary and after fertilisation the embryo travels down the tube to the uterus.

**Fecundity:** The ability to reproduce.

**Fertility intentions:** The number of biological children a woman aspires to have in her lifetime.

**Fertilisation:** The penetration of the ovum by the spermatozoon and combination of genetic material resulting in the formation of a zygote.

**Foetus:** The product of fertilisation from the completion of embryonic development at eight weeks after fertilisation until abortion or birth.

**Fresh cycle:** An ART treatment cycle that intends to use, or uses embryo(s) that have not been cryopreserved (frozen).

**FSH:** Follicular stimulation hormone is produced by the pituitary gland and controls the production of oestrogen by the ovaries.

**Genomic imprinting:** Mechanism of DNA methylation controls which genes are expressed in certain cell types. Many imprinted genes play an important role in embryonic growth, placental function and neuro-behavioral processes. Certain genes are expressed in a parent of origin in a specific manner. If an allele inherited from one parent is imprinted it is silenced and only the allele from the other parent is expressed.

**ICSI:** Intracytoplasmic sperm injection was developed in 1990 for male factor infertility. ICSI technique injects a single spermatozoon into an oocyte cytoplasm.

**Implantation:** The attachment and subsequent penetration by the zona-free blastocyst that starts five to seven days after fertilisation.

**Infertility:** Failure to achieve a clinical pregnancy after 12 months or more of regular unprotected intercourse.

**In vitro fertilisation:** IVF is a procedure within ART that involves extracorporeal fertilisation. Fertilisation occurs outside the body.

**LH:** Luteinising hormone is produced by the pituitary gland and controls the length and sequence of a menstrual cycle. A midcycle surge of LH triggers ovulation.

**Live birth:** A live birth is defined as a birth past 20 weeks gestation and the babies survival for longer than 28 days.

**Low birth weight:** A birth weight of less than 2,500 grams.

**Karyotype:** The number and visual appearance of the chromosomes in the cell nuclei of an organism.

**Midlife intending mothers:** A term used in this research describing women aged 35 years or older using ART to conceive.

**Miscarriage:** A pregnancy with a gestational sac that fails to progress past 20 weeks of gestation. Miscarriage frequently occurs in the first trimester but can occur within the first few weeks of conception.

**Monosomy:** A chromosome is missing.

**Neonatal death:** Death of live born infants within 28 days of birth.

**NPESU:** National Perinatal Epidemiology and Statistics Unit.

**Nulliparous:** Woman who has not carried a pregnancy beyond 20 weeks.



Oocyte: A female reproductive cell.

Oogenesis: The creation of a single ovum (egg cell)

OHSS: Ovarian hyperstimulation syndrome is an adverse complication of ovulation stimulation therapy, after the administration of follicle stimulating hormone (FSH). OHSS symptoms include abdominal distension, ovarian enlargement, and respiratory, haemodynamic, and metabolic complications.

Ovarian follicles: A granulose cavity or recess in an ovary containing a mature ovum surrounded by cells.

Oviduct: Passageway from the ovaries to the uterus where the ovulated oocyte travels to potential fertilisation. Also known as the fallopian tube.

Parity: The classification of a woman in terms of the number of pregnancies that have reached 20 weeks or longer gestation.

Parous: A woman who has delivered a viable baby after at least of 20 weeks gestation.

Partnering: A significant relationship with a male, but not necessarily in a legal marriage.

PBS: Pharmaceutical Benefits Scheme.

PGD: Preimplantation genetic diagnosis involves testing for specific genetic conditions in an embryo created using ART to identify conditions of risk prior to transferring it to the uterus.

PGS: Preimplantation genetic screening involves screening for many genetic conditions in an embryo created using ART to identify conditions of risk prior to transferring it to the uterus.

Perinatal death: Foetal or neonatal deaths (stillbirths) occurring during late pregnancy (at 20 weeks gestation or later), during childbirth or up to 28 days after birth.

Primary infertility: Never conceived.

QFG: Queensland Fertility Group.

Secondary infertility: Subfertility after a pregnancy.

RTAC: Reproductive Technology Accreditation Committee of the Fertility Society of Australia.

Recipient cycle: An ART treatment cycle in which a woman receives oocytes or embryos from another woman.

SGA: Small for gestational age.

Spontaneous miscarriage: The spontaneous loss of a clinical pregnancy before gestational age of 20 weeks or the loss of an embryo/foetus of less than 400g.

Trophectoderm: Outermost layer of cells in the mammalian blastodermic vesicle, which will make contact with the endometrium and take part in establishing the embryo's means of receiving nutrition; the cell layer from which the trophoblast differentiates.

Trisomy: Chromosomal disorder caused by the presence of all, or part of, an extra chromosome. Three copies of chromosome results in a total chromosome number of 47 instead of 46.

Zona pellucida: The extracellular coat that forms around an ovum as it develops in an ovary. It has a vital role during oogenesis, fertilisation and preimplantation development. A sperm needs to penetrate the zona pellucida for fertilisation to occur.

Zygote: A diploid cell formed after fertilisation between a sperm and oocyte and is the earliest developmental stage of an embryo.

## **Chapter 1: Assisted Reproductive Technology for women in midlife**

The aim of this research is to investigate beliefs and expectations along with social reasons for women delaying childbearing, and perceptions of the success of Assisted Reproductive Technology (ART). In addition, it seeks to explore the experiences of women who have undertaken ART. This research was designed to fill a gap in the body of knowledge about the use of ART services by women in midlife through two Australian infertility clinics. The evaluation of beliefs and expectations are viewed from a public health perspective.

Chapter One provides an introduction to the research. It includes the significance and rationale of the study, an introduction to the medical procedures of ART, including Australia's role in ART, a review of research undertaken into Australian women's beliefs about, and engagement with, ART and an outline of the research.

### **1.1 Rationale**

In the Australian context, there is limited research on women undertaking ART, particularly women in midlife when their fertility is substantially waning. Little is known about the perceptions and expectations of these women about ART, the factors that have informed their expectations, and how these expectations may change when they engage with infertility treatment. The research compares the beliefs and understandings of the general public with those of female patients of an infertility clinic.

Women in Australia are having children at an age later than in previous years (Australian Bureau of Statistics, 2012b). While female fertility has been postulated to decline from as young as 32 years of age, 35 years of age is accepted as the period of significant decline (American Society of Reproductive Medicine, 2014). Older women have age-related infertility that arises from chromosomal changes in their oocytes. Childbearing for midlife intending mothers has health implications for the mother and baby (Baart et al., 2006). Midlife intending mothers also have an increased risk of adverse maternal, foetal or infant outcomes, smaller family size than desired, higher chance of miscarriage, as well as involuntary childlessness (Daniluk & Koert, 2015). It has been documented that older women have higher rates of instrument birth, neonatal complications, caesarean delivery, gestational diabetes, and low birthweight babies. Information on the increased risks for women who delay childbearing or use ART is not widely understood in the community.

Women delaying childbearing may believe that ART can overcome age-related infertility and seek to use it as a fall-back option (Hashiloni-Dolev, Kaplan, & Shkedi-Rafis, 2011; Weston, Qu, Parker, & Alexander, 2004). Some women may be unaware of age-related fertility decline or have unrealistic expectations of ART and experience involuntary childlessness or fewer children than anticipated. To make informed decisions it is imperative women have a substantial understanding of the risks of delaying pregnancy

Widespread access to contraception frees women to decide when to have children; some delay childbearing based on social factors or personal beliefs. Australian women's childbearing intentions and reasons for having children in later life have been explored. Some influences include: not being in a partnered relationship, educational pursuits, and career or work aspirations. Influences may be shaped by circumstances and may not have been well-considered (Holton, Fisher, & Rowe, 2011a). The medical profession understands the evidence that normal ageing impacts upon likelihood of a conception. However, the proposition exists that this is not fully understood within the community.

ART-conceived babies accounted for 4.1% of Australian births (Li, Zeki, Hilder, & Sullivan, 2012). In the reproductive context, this is important, as an increasing number of women are delaying childbearing until midlife (Billari et al., 2011). This is an age when they are unlikely to conceive without fertility treatment and thus risk involuntary childlessness (Leridon, 2008). Women need reliable and accurate knowledge of the success and risks of ART to make decisions about childbearing. Information about age-related fertility decline, ART procedures, costs and success rates (reported in a manner able to be comprehended by non-experts) should be freely available. Women may believe they are informed but may not be fully informed, and become aware of risks only when pregnant. Those who are informed may also choose to delay childbearing (Cooke, 2010). A lack of awareness of the cause of decline in fertility may influence some women to delay childbearing until they are unwittingly reliant on medical intervention. Women may not be aware of health risks when undertaking ART. Some, aware of the danger of delaying childbearing, may take the chance, perhaps buoyed by the perception, through the media, that medical technology will circumvent problems. However, this confidence may be unjustified.

A lack of knowledge of infertility and success rates of ART are a problem for Australian women. The number of women accessing ART is increasing annually and the age of women requiring ART is rising. More needs to be known about the needs and expectations of this group. Determining the level of knowledge surrounding these issues can benefit

young women in the community. Exploring the experiences of women who have used ART can provide insight and knowledge to improve IVF services. An understanding of the limitations of female fertility may encourage women to start their families before their fertility declines. Fewer women with age-related infertility requiring ART and achieving their personal childbearing aspirations is in the public interest.

Growth in the number of women aged 35 years or older using ART has increased expenditure in the Australian healthcare system. In the context of age-related infertility, the chance of pregnancy is small, particularly for women with declining fertility. Johri and Lehoux (2003) argue that ART reflects a dilemma by using expensive medical technologies that benefit a small number of people. Neumann (1997) suggests that resources for ART should be allocated to couples with a higher chance of success from clinics with high success rates. A health technology assessment of the social value versus the cost of ART is difficult as the interpretation of value is different from a societal value compared with personal desire for a child (Johri & Lehoux, 2003). Within the Australian context, ART could be interpreted as an expensive technology for a few beneficiaries (van Gool, Savage, Viney, Haas, & Anderson, 2009).

## **1.2 Background**

In this research, midlife intending mothers are defined as women giving birth or trying to conceive when aged 35 years or older (Berryman & Windbridge, 1997). This group have a higher risk of age-related chromosomal changes in their oocytes and a higher reliance on ART compared with younger women.

The research sought to obtain the personal stories and beliefs of women who have used ART. Data were sought regarding women's optimal age for childbearing, perceptions about their ART experience, prior expectations, the success rate of ART and whether their beliefs are shaped by preconceptions gained from media or marketing. The community, who in the majority would not have used ART, were also questioned about their views of the optimal age for women to have children, beliefs on the success of ART, and whether media has influenced their views. The research also examines whether environmental influences have impacted the childbearing intentions of Australian women.

The study seeks to provide insight and extend the body of knowledge about the phenomena of midlife intending mothers and community beliefs regarding ART. Views of Queensland women aged 35–52 years who had engaged with ART and men and women

aged 18–82 years in the Queensland community were compared. Data on women accessing ART is available through perinatal statistics compiled from the Australian and New Zealand Assisted Reproductive Databases (ANZARD). ANZARD data includes; the age of women having ART, number of cycles, pregnancy rates, birth rates, miscarriage rates, birth outcomes and other data pertaining to ART cycles (Macaldowie, Lee, & Chambers, 2015). However, empirical data lacks social perspectives and social research surrounding ART is limited due to privacy issues and limited researcher access to patients in private clinics. Some women find the psychological consequences of infertility and ART treatment taxing and can be reluctant to discuss their personal stories.

Women may not fully grasp the fertility implications of delaying childbearing and chances of conceiving with ART and may be denying themselves the opportunity for motherhood. As Lord Robert Winston notes “infertility is not a disease but a natural process” and “in vitro fertilisation (IVF) cannot cure infertility” (McLaren, 2014). This statement may be perceived as controversial as some causes of infertility may be due, for example, to blocked fallopian tubes or genetic conditions (Khetarpal & Singh, 2012); however, it is important to note that ART cannot cure age-related chromosomal changes in oocytes (Lim & Tsakok, 1997). Perceptions of the success of ART for midlife intending mothers can be unrealistically elevated through media and marketing. As medical advances are made in reproductive technology, women’s expectations of the success of ART may be elevated. However, the power of marketing by infertility clinics and pharmaceutical companies, and media’s tendency to overestimate the capability of ART has led to global misinformation that overrides the limitations of ART (Zoll & Tsigdinos, 2013). Australian women may perceive ART as a fall-back option (Norman, 2007; Weston & Qu, 2005). Consequently, women who believed they would have children may have unintentional childlessness. Awareness of the relationship between increasing maternal age and decreasing childbearing potential allows women to make informed choices about childbearing.

ART is an expensive medical procedure and is available mainly in privately owned clinics. Australian women can undertake unlimited ART cycles provided they fund the out-of-pocket expenses of treatment. The cost of ART is subsidised through Medicare and the Pharmaceutical Benefits Scheme (PBS) and the out-of-pocket expense per treatment cycle is considerable (Chambers & Sullivan, 2005). Despite the availability of unlimited funded cycles, Australian research into cumulative live birth rates shows there is little chance of pregnancy after the fifth cycle of ART regardless of a woman’s age (Macaldowie, Wang, Chambers, & Sullivan, 2013). Live birth per ART cycle rate indicates

that less than one in five women aged 35 years or older will conceive (Macaldowie, Wang, Chughtai, & Chambers, 2014; Weston et al., 2004). Unlimited Medicare-funded cycles for women who have a marginal chance of birth are problematic for Australian health care funding.

Australian infertility clinics are private companies; some owned by venture capital companies and listed on the Australian stock exchange and some privately owned (Gardner, 2014a, 2014b, 2014c). The research questions whether infertility has become commodified and how this impacts on patient care. The Australian Financial Review, on August 20<sup>th</sup>, 2015 (Whyte, 2015), cites discontent within medical practitioners and embryologists with an IVF clinic, which was purchased by a venture capital company in 2009. Clinicians and embryologists were concerned that the company was moving away from the core values of the clinic leading to a lack of clinician input into patient care, rising treatment costs, and hiring of new IVF specialists. As smaller infertility clinics become absorbed into larger clinics, questions arise regarding the potential for compromised patient care arising via corporatisation.

### **1.3 Barriers to Conception**

Infertility can have multiple aetiologies, either male or female, or a combination of both. In 2013, of the more than 70,000 initiated autologous (using a women's own oocytes) and recipient cycles (using donated oocytes or embryos), 20.9% involved male infertility only, 27.9% female factors, and 13.3% a combination of male and female factors with 22% idiopathic and 15.6% from unknown factors (Macaldowie et al., 2015). Reduced semen parameters are an important factor in couples attending infertility clinics; however, for this research, female age-related infertility is the focus.

Women are increasingly delaying their age of childbearing compared with their mothers and grandmothers. In Australia, the average maternal age is 30.1 years of age, the average age of first time mothers is 28.6 years of age, and 22% of first time mothers are aged 35 years or older (Li, Hilder, & Sullivan, 2015). The average age of women undergoing ART autologous cycles in 2013 was 35.9 years and 26.8% of women were aged 40 and older, an age when fertility is significantly compromised (Macaldowie et al., 2015).

Women may be delaying childbearing for many reasons and there is no consensus for this trend. For many women, social factors combined with a lack of understanding of age-

related fertility decline can lead to involuntary childlessness (Van Balen & Inhorn, 2002). Australian research indicates that social reasons such as career and educational goals, desire for financial security, and volatility of parenting relationships may be significant factors for women contemplating childbearing in midlife (Weston & Qu, 2005). To have a 90% chance of a single naturally conceived birth, women should commence childbearing before the age of 35 years. However to have two naturally conceived children, women should start their families at age 31 years, and for three children, 28 years. These age limits may be unknown in the community (Habbema, Eijkemans, Leirdon, & te Velde, 2015)

Many women who delay childbearing have a reduced chance of conception, a higher chance of pregnancy loss, and increased health risks for themselves and their baby. Midlife intending mothers are more susceptible to miscarriage or having a baby born with a significant chromosomal impediment (Baart et al., 2006). Irrespective of the initial infertility aetiology, maternal age affects oocyte quality and quantity, and age is the most important factor influencing the success or failure of ART (Damario, Davis, & Rosenwaks, 1999; Handyside et al., 2012; Harton et al., 2013; Krey, Zhang, & Gfiro, 2001; Sauer, 2015). Because women are born with their lifetime complement of oocytes and age-related changes are caused by chromosomal variations, increasing maternal age is associated with detrimental changes.

#### **1.4 ART**

The Fertility Society of Australia's website (Fertility Society of Australia, 2005) defines infertility as "the inability of a couple to achieve conception after a year of unprotected intercourse, or the failure to carry pregnancies to a live birth." The World Health Organization's website (World Health Organization, 2016) defines infertility as "a disease of the reproductive system defined by the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse". ART was developed to bypass biological impediments to conception (Wang, Chambers, Dieng, & Sullivan, 2009) by manipulation of reproductive cycles, oocytes, embryos and semen to aid conception (Reed, 2001). In in-vitro fertilisation (IVF), the fertilisation of egg by sperm occurs outside the body (in vitro) and a fertilised embryo is transferred to the uterus (Rowell & Braude, 2003). It may assist idiopathic (unexplained) infertility or at least reveal the impediments to conception (Rowell & Braude, 2003; Sandelowski, Holditch-Davis, & Harris, 1990). ART is



an expensive and invasive treatment. It generally does not cure infertility but attempts to circumvent obstacles to conception (McLaren, 2014).

In Australia, one in six couples are unable to conceive spontaneously after a year of timed, unprotected intercourse and may seek medical advice from infertility clinics (Australian Broadcasting Corporation, 2014; Fertility Society of Australia, 2005; Kersten et al., 2015a). Herbert, Lucke and Dobson (2012) discuss the term “subfertility” and suggest that many women may self-diagnose infertility when they are subfertile and may conceive without intervention, although a conception may take longer than 12 months. However, this option may not be suitable for older women, as waiting may be detrimental to oocyte quality.

In a natural cycle, the ovary releases an oocyte into the fallopian tube at ovulation. For a natural conception, sperm and oocyte must mix in the oviduct, a sperm penetrates through the zona pellicuda (the outside of the oocyte), and fertilisation occurs (Rijinders et al., 1996). The fertilised zygote passes down the fallopian tube to the uterus for implantation into the uterine wall.

In ART, a women’s reproductive cycle is artificially manipulated to produce multiple oocytes in a cycle. The natural ovarian function is shut down at the pituitary level from day 20 of the preceding cycle with nafarelin acetate or from day 2 of the current cycle with leuprolide acetate. Down-regulation of the pituitary gland is required to prevent the surge of luteinising hormone and to block the accidental release of the oocyte from the ovaries before surgical oocyte collection (Rowell & Braude, 2003). Follicle growth is stimulated by subcutaneous injections of follicle-stimulating hormone (FSH) analogues. Oestradiol levels are monitored daily by blood tests. Typically, about ten days of FSH injections will be required before oocyte collection. Ultrasounds monitor follicular growth and human chorionic gonadotropin (hCG) is administered to initiate oocyte maturation. A transvaginal retrieval procedure, which requires a general anaesthetic, is scheduled approximately 36 hours after the hCG injection to recover oocytes from the ovarian follicle. However, not all stimulated cycles will proceed to oocyte collection because of inadequate response to the ovarian stimulation and lack of oocyte maturation (Braude & Rowell, 2003a, 2003b; Templeton, Ashok, Bhattacharya, Gazvani, & Hamilton, 2000).

The oocyte then completes a secondary meiotic division to form a mature oocyte, which is then capable of being fertilised by sperm. Oocytes are placed into a culture medium to promote cell division, and sperm is mixed with the oocytes in a petri dish or a single sperm may be injected into the oocyte via Intracytoplasmic Sperm Injection (ICSI). The

appearance of two pronuclei after 24 hours indicates that fertilisation has occurred and the embryo is dividing. Embryo viability is graded and either two-to three-day-old embryos (containing six–eight cells), or blastocysts (embryos five days after collection) are transferred to the uterus through the cervix using a catheter (Jansen, 2003). Hormonal support in the form of supplementary progesterone assists the implantation of the embryo into the uterus (Braude & Rowell, 2003a, 2003b; Hartshorne, 1999). If a menstrual period has not occurred within two weeks after embryo transfer, a blood test showing elevated levels of beta hCG indicates a biochemical pregnancy. Detection of a foetal heartbeat at six weeks gestation confirms a clinical pregnancy (Braude & Rowell, 2003a, 2003b; Templeton et al., 2000).

There are two narratives of the outcome of ART – either “happy” or “hopeless”. The happy narratives are for the much-anticipated baby born to a grateful mother but happy stories are problematic for those women who do not conceive, which is the majority of older women (Franklin, 1990). Hopeless narratives are not openly discussed or embraced by media, compared with success stories. Some childless women place the burden of blame and guilt upon themselves and happy perceptions perpetuate women’s sense of failure (McLaren, 2014; Sandelowski et al., 1990).

Most research into infertility, involuntary childlessness and ART relate to women within a high-income context where motivations for having children may arise from the search for personal happiness or goals, yet the motivation of continuity and care for parents in old age are less frequently mentioned than in non-Western societies (Van Balen, Verdurmen, & Ketting, 1995). Low-income societies have different social and economic reasons for having children such as for social security by financial or labour contributions of offspring, social powers sources for women in patriarchal societies, or social perpetuity or kinship reasons (Inhorn, 2006). Low-income societies do not always view having children as a lifestyle option, but necessary for social support.

## **1.5 Evolution of ART in Australia**

Australian scientists have been at the forefront of ART research and although the birth of the first ART baby occurred in the UK (Steptoe & Edwards, 1978), the race for that first pregnancy was strongly contested by Australian medical teams (Brisden, 2009). In the 1970s, Drs. Carl Wood and Alex Lopata attempted an IVF cycle but the oocytes failed to fertilise (Dawson, 1994). Candice Reed was born in 1980, and was the third baby in the world to be born through ART and Australia’s first ART baby. In 1980, Monash IVF had an

ART breakthrough by initiating stimulated cycles, which increased the number of oocytes produced, thus improving the pregnancy rate from 2% to 18% per cycle. Australian clinics achieved the first ART twins in 1981, triplets in 1983, and quadruplets in 1984 (Dawson, 1994; Rowland, 1992). Melbourne scientist Alan Trounson developed cryoprotectants, which prevented ice crystals forming in cells causing rupture of the cell membrane, and slow-rate freezing protocols to allow storage of surplus embryos that improved success rates (Cohen, Trounson, Dawson, & Jones, 2005). The technique of frozen embryo transfer (FET) enabled excess embryos to be transferred in subsequent cycles without the need for ovarian stimulation and resulted in the world first live birth from FET (Dawson, 1994). Chambers, Illingworth and Sullivan (2011) suggest that Australian infertility clinics work to increase success rates by improving culture media and techniques. However, a systematic review of randomised controlled trials on the effect of culture media on success rates for IVF/ICSI has not determined a significant improvement (Mantikou et al., 2013).

There are no restrictions on the number of ART cycles that Medicare will fund, and Australia is the only Western country without cycle limitations. Many infertility clinics have transformed from small clinician run practices to large multi-site clinics and some run by venture capital companies and listed on the stock market (McCullough, 2010; Thompson & Connors, 2011). The ART business is very profitable and encompasses a high percentage of the Medicare budget for only a small number of patients compared with other Medicare funded services such as general practitioner consultations (van Gool et al., 2009).

In 2013 in Australia and New Zealand, over 37,000 women undertook treatment cycles, with 23.8% resulting in pregnancies and 18.2% proceeding to a live birth for women of all ages (Macaldowie et al., 2015). ANZARD annual data shows variation in success rates between clinics, with some more successful than others. Many clinics publish cumulative data results giving the impression of a higher success rate overall compared to per-cycle success rates. The complexity of the data and being able to compare published success rates between clinics can be confusing for the consumer and is currently being reviewed by the Australian Competition and Consumer Commission (Whyte, 2015).

## **1.6 An overview of previous Australian research into older women and ART**

Previous Australian researchers in this area have previously focused on quantitative research on women and childbearing rates. There has been minimal research into the social issues around midlife intending mothers accessing ART, particularly from a qualitative perspective. Key Australian researchers who have evaluated women's

childbearing intentions are Cannold, Hammarberg, Kimberley-Smith and Weston. The thesis builds on research initiated by these researchers by further examining the views of a broader section of the community along with consumers of ART. A study by Hammarberg and co-authors (2001) researched past clients of an infertility clinic and a group of women undertaking ART (Hammarberg & Clarke, 2005). Hammarberg, Setter, Norman, Holden, Michelmore and Johnson (2013) examined men and women about their beliefs in the age of fertility decline. Cannold's (2000) 35 participants from North America and Australia had not all received ART treatment and Cannold investigated how childlessness is experienced and understood. Weston and colleagues (Weston & Parker, 2002; Weston & Qu, 2001, 2005; Weston et al., 2004; Weston, Stanton, Qu, & Soriano, 2001) surveyed a sample of the general population about their attitudes to childbearing, and Kimberley-Smith (Kimberley-Smith 2003) surveyed undergraduate students.

Leslie Cannold (2000, 2005) is an Australian researcher who has undertaken qualitative research on women's views on childbearing and childlessness. Her research suggests that women may have reasons for delaying childbearing that extend beyond their control and may be contrary to their desires and aspirations for parenthood. Cannold (2000, 2005) stressed the importance of relationship stability in relation to women's intentions to have children and reported that stability in career, relationships and financial security were seen to be important issues for women before they had children. Women who chose to pursue their education and career when aged in their 30s may not be able to find a suitable partner when they feel ready to have children. If they do not wish to be a sole parent, they may then find themselves becoming childless through circumstance and not by choice.

One of the Australian studies involving women attending an infertility clinic was a study of women attending a clinic in Melbourne (Hammarberg & Clarke, 2005). Of 152 female participants, 18% were unaware that the chances of having children was age-dependent, and 50% cited lack of a relationship as their prime reason for delaying childbearing. The study found that women might desire career, financial, or partnering relationships before they started a family or have health issues which precluded them from conceiving without difficulty.

Kimberley-Smith (2003) found a lack of knowledge about biological limitations on women's fertility amongst young female Australian university students. Most were confident that ovulating women could achieve a pregnancy regardless of age as long as they were menstruating. Students believed that, if women delayed childbearing and subsequently

had trouble conceiving, ART would be able to help them achieve a pregnancy. This study suggested that young women's expectations of ART at the time were strong and positive. This was a prospective study involving young Australians and participants were selected from a narrow population. Consequently, generalisation of their beliefs and opinions to the broader population and to women already experiencing infertility would benefit from further investigation.

Other researchers have reported the many reasons why more Australian women appear to be delaying their childbearing compared with previous generations (Merlo, 1995; Merlo & Rowland, 2000; Qu, Weston, & Kilmartin, 2000; Weston & Qu, 2001; Weston et al., 2004). Researchers have investigated social reasons for women approaching motherhood in midlife (Rindfuss & St.John, 1983; Stolka & Barnett, 1969; Summers, 2003; Weston et al., 2004). Educational attainment, lack of partnering relationship (Cannold, 2000; Weston et al., 2004) and financial costs of raising children (Qu et al., 2000), were found to be some reasons for delaying motherhood. Research findings indicate that younger women (aged 20–29 years) were more likely than older women (30 years of age or older) to emphasise the importance of being able to provide a secure financial upbringing for a family before having children (Weston et al., 2004). Younger women may choose to postpone childbearing to fulfil these expectations. Living in an urban or rural region in Australia has also been identified as relevant to childbearing decisions because women in capital cities are having their first child two years later than are women from regional areas (Australian Bureau of Statistics, 2000).

Some studies with the general community have been undertaken such as Weston and Qu (2005) who used a telephone survey to investigate the opinions of Australian men and women aged 20–39 years of age about the use of ART. Respondents were childless and not using ART at the time. They found more than 40% of the participants anticipated they would use ART if they had problems conceiving. Men had greater expectations of success than women. Women aged in their late 30s were just as likely to have hopes of achieving a pregnancy with ART, as younger women. The authors suggested that, because many believed they would have success using ART, such optimism might strengthen beliefs that childbearing could be postponed. The researcher prior to candidature at the University of Queensland Medical School presented the study overview at the XV International Congress of the International Society of the Psychosomatics Obstetrics and Gynecology Conference in Kyoto, Japan in 2007 (Hayward 2007a,b). A poster was presented at the

Population Health Congress - A global world-practical action for health and wellbeing in Brisbane in 2008 (Hayward, 2008).

These studies support further investigation into women's expectations of ART.

## **1.7 Significance Of The Problem**

In the Australian context, there has been limited research on women undertaking ART, particularly women in midlife when their fertility is substantially waning. Little is known within this context about the beliefs and expectations these women have of ART, the social factors that have informed their expectations, and how these expectations may change in the period during which they engage with ART. This research looks into women of an age that leads them to be users of ART treatment which, in Australia, is a public health concern. This research compares the beliefs and understandings of the general public with those of female patients of infertility clinics. Two clinics were chosen to avoid too much emphasis on the culture of a single institution.

ART conceived babies accounted for 4.1% of Australian births (Li et al., 2012). As this is an age when they are unlikely to conceive without fertility treatment and thus risk involuntary childlessness (Leridon, 2008). Childbearing for midlife intending mothers has health implications for the mother and baby (Baart et al., 2006), and older women have higher rates of instrument births, neonatal complications, caesarean delivery, gestational diabetes, and low birth weights babies. Delaying childbearing has health risk implications for mother and child, even more so for ART-conceived pregnancies (Becker, 2000; Cnattingius, Berendes, & Forman, 1993; Gilbert, Nesbitt, & Danielsen, 1999; Hollander, 1999; Snijders, Sebire, & Nicholaides, 1995; Viot, Epelboin, & Olivennes, 2010). Increased risks for women who delay childbearing or use ART is not widely appreciated in the general community.

Some of the influences for delaying childbearing include: not being in a partnered relationship, educational pursuits, and career or work aspirations. These factors have been explored in the Australian context (Cannold, 2000; Hammarberg & Clarke, 2005; Weston & Qu, 2001). Women's childbearing intentions may be shaped by such influences and may not be a rational decision as demonstrated in Holton's (2011a) study which showed that 80% of Australian women aged 30-34 years had fewer children than desired.

Based on the relevant literature, this thesis presumes, that some women of childbearing age may make informed or uninformed decisions on the timing of childbearing. Women may believe they are informed on the risks associated with delaying motherhood, (Cooke, 2010). A lack of awareness of the cause of the decline in fertility may influence some women to delay their childbearing until they are reliant on medical intervention by ART as the only way to conceive a child. Women may not be aware of health risks for women undertaking ART and their babies. Some women are also aware of the danger of delaying childbearing but take the chance, maybe buoyed by the perception through the media that medical technology will circumvent these problems, however, this confidence may be unjustified.

Johri and Lehoux (2003) argue that ART reflects a dilemma between expensive medical technologies which benefit a small number of people against the benefit it gives for the users of the technology. Some health insurers in the USA argue that infertility is not medically necessary to preserve health and limit the medical coverage of ART while others accept that it is a disease of the reproductive system. Neumann (1997) suggests that resources for ART should be allocated to couples with a higher chance of success and using clinics with higher success rates. A health technology assessment of the social value versus the cost of ART is difficult as the interpretation of the value is different from a societal value compared with the individual value of yearning for a child (Johri & Lehoux, 2003). Within the Australian healthcare context, ART could be interpreted as an expensive technology with few beneficiaries (van Gool et al., 2009).

The growth in the numbers of women accessing ART has resulted in an increase in expenditure to the Australian healthcare system as infertility treatment is funded through Medicare. Although the desire for a child is emotive, in reality ART does not guarantee success, and in the context of age-related infertility, the chance of pregnancy is small. The increasing demand for ART services has implications for expenditure in the public health system and ongoing formation of public health policies and education about fertility limitations. An understanding of influences on delaying childbearing, experiences, and success rates can provide data for health educational programs and social strategic initiatives.

## **1.8 Organisation Of The Thesis**

This study aims to ascertain whether the community holds accurate beliefs about infertility and its treatment and questions whether media or clinic marketing information influences

community perceptions. It explores these concepts among women who had engaged in ART along with their experiences.

Chapter 2 presents the theoretical framework for the study and introduces the idea of medicalisation and of infertility, where commodification is the transformation of services or entities into a commodity. The theory of anticipated decision regret is proposed as it relates to decisions to discontinue treatment.

Chapter 3 presents a literature review of childbearing in Australia. This chapter reviews childbearing practices, beliefs and social factors that influence or limit women's childbearing decisions.

Chapter 4 is an overview of the ART industry in Australia. ART success rates and medical risks for midlife intending mothers and babies from either natural or ART-assisted pregnancies are detailed. The medical literature on physiological changes attributed to genetic changes in women's oocytes because of biological aging is reviewed. Psychological aspects of undertaking ART are discussed within the context of infertility clinics who are marketing hope for a woman to start a family. The history of public funding for ART and lack of restrictions on cycles is described.

Chapter 5 outlines the research methodology, including methods of data collection and analysis. Qualitative and quantitative data were collected from three sources; two infertility clinics and community members in Queensland.

The subsequent four chapters present the research data and its analysis.

Chapter 6 evaluates survey data collected from women who had used ART using an online questionnaire investigating key measures linked to the research questions.

Chapter 7 evaluates survey data collected by telephone survey from 1243 men and women in the community. The group was asked five key questions, and their overall responses are analysed according to gender and age group.

Chapter 8 explicitly compares and contrasts five key questions from survey data in Chapters 6 and 7.

Chapter 9 presents analysed qualitative data gathered from six women who participated in face-to-face interviews. Common themes arising from the analysis of their views, expectations, and experiences are discussed.



Chapter 10 includes the conclusions and recommendations arising from the research. This chapter also reviews the limitations of the investigation and presents recommendations for further study based on findings from this study.

Chapter 11 outlines recommendations to younger women in the community based on data from the research.

## **1.9 Research Questions**

The following eight questions were investigated in this research.

1. What are the views of women who have engaged with ART about their clinic experience?
2. What were women's expectations of the success of ART?
3. What are the views of women involved with ART on women's age-related fertility decline, childbearing decisions, the success of ART and impact of media and marketing on childbearing decisions?
4. What are the beliefs of the community towards women's age-related fertility decline, childbearing decisions, success of ART and impact of media and marketing on childbearing decisions?
5. Do social factors such as; career and work, educational attainment, financial security, health or partnering relationship influence women's childbearing intentions?
6. Is there a perception among the general population and consumers of ART that infertility is medicalised and its treatment commodified?
7. What are the social and psychological impacts for women using ART?
8. Do women who have engaged with ART have recommendations for women in the community regarding the timing of childbearing and ART?

## **1.10 Summary**

This research attempts to build upon and extend existing Australian research and findings from other Western cultures. It examines the experiences, expectations of ART, and knowledge of age-related infertility and ART for midlife intending mothers in Queensland. It compared this with beliefs about and knowledge of age-related infertility and its treatment within the general community.

Accurate information on age-related decline in women's fertility and a realistic understanding of chances of a baby using ART are important issues. Such

information allows individuals to make considered decisions on timing of childbearing. Women able to conceive spontaneously do not incur the physical, psychological, and financial challenges of ART.

## **Chapter 2: Theoretical framework of the research**

### **2.1 Overview**

This chapter introduces several themes supporting the research. These are the medicalisation of healthcare and ART, concepts of disease and technology mongering, the commodification of ART, and the theory of anticipated decision regret. The idea of medicalisation applies when health or social issues are reclassified as medical conditions thus requiring medical intervention (Conrad, 2004). As a consequence of medicalisation, health care becomes commodified, with positive fiscal outcomes for pharmaceutical companies and medical practitioners. This chapter examines the rise of over-medicalisation in high-income societies. The medicalisation and commodification of infertility within the Australian context is discussed. Tymstra's theory of anticipated decision regret (Tymstra, 1989, 2007) is considered in relation to the difficulty of some women to discontinue ART treatment without experiencing regret.

### **2.2 Medicalisation**

In simple terms, medicalisation narrows the definition of health and widens the definition of sickness (Conrad, 2004). Conrad suggests that medicalisation encompasses "defining a medical condition in medical terms, usually as an illness or disorder, or using medical intervention to treat it" (Conrad, 2005:3). Similarly, medicalisation occurs when human experiences and conditions are defined as medical problems, and there is a tendency to classify some non-medical social issues as medical conditions (Australian Broadcasting Corporation, 2014; Becker & Nachtigall, 1992; Conrad, 1992; Hassan, 2006; Williams & Calnan, 1996a; Zola, 1972). Medicalisation operates with the framework of the medical model based on empirical data and without reference to social factors (Brennan, Eagle, & Rice, 2010; Filc, 2004; Lupton, 1997; Nettleton & Gustafsson, 2002) and has implications for social control, power and liberty (McGann & Conrad, 2007). It is proposed "growth in the number of medical conditions reflects the dominance of medicine and the significance of illness in defining social deviance" (Abraham, 2010:290). Medicalisation can also emerge after "health scares" which lead to social anxiety as "events in which the health of a population or a significant subpopulation is at risk to an uncertain and potentially devastating degree" (Hooker, 2010:8).

Whereas the concept of medicalisation was originally associated with the medical dominance of the medical profession, this is changing in the postmodern era. Today medical consumers have access to online medical information, and as a consequence, are more informed and able to access peer-reviewed research (Cline & Haynes, 2001). As the dominance and power of the medical profession declines, consumers can choose to resist or embrace medicalisation (Ballard & Elston, 2005).

There are three primary progenitors of medicalisation. The first is conceptual in which a biomedical framework is used to define a problem that was once considered non-medical. The second is institutional in which organisations prefer medical rather than non-medical approaches to treating a problem. The third is interactional in which a socially linked factor is treated with medical intervention (Brennan et al., 2010; Conrad, 2005; Moynihan, Heath, & Henry, 2002). In recent times the medical profession has become closely aligned with those who profit from the marketing of pharmaceuticals for new diseases or medical conditions, and can no longer be regarded as an objective agent (Godlee, 2010). Relationships can be fostered through informal alliances between; pharmaceutical companies, public relations companies, doctors groups, and patient advocate groups, which actively market through the media (Moynihan & Henry, 2006). Conrad (2004) believes that the push towards medicalisation comes more from the creation of medical markets for financial gain than from the medical profession wishing to expand its market professionally.

The number of normal human conditions that are regarded as medical diseases is increasing. There is also an increase in pre-symptomatic conditions linked to a statistical likelihood where a medical condition (such as elevated cholesterol, mild diabetes or high blood pressure) may develop in future (Cassels, 2007; Greene, 2007). Tiefer (2006) suggests that the community finds medicalisation attractive as it presents understandable scientific solutions for medical conditions and there seems to be overinvestment in biological explanations of conditions and their interventions. Medicalisation also occurs if the public has a low tolerance of personal discomfort and refers to the medical profession for treatment by pharmaceuticals (Barsky & Boros, 1995).

Some examples of medicalisation are documented in the literature, including restless leg syndrome (Woloshin & Schwartz, 2006), and male erectile dysfunction (Conrad, 2005). In particular, women's natural reproductive functions of menstruation, pregnancy, childbirth and also mental illness have become routinely medicalised (Barker, 1998; Conrad &

Barker, 2010; Riessman, 1983). Menopause was medicalised from the 1970s as a deficiency disease, and consequently, oestrogen has been the fifth most commonly prescribed pharmaceutical in the USA (Ballard & Elston, 2005; Conrad, 2007; McCrea, 1983). The medicalisation of obstetric practice has increased since the 1960s when control of birthing shifted from midwives to obstetricians (Macintyre, 2008; Riessman, 1983). The increasing number of instrumental births, hospital births, and use of anaesthesia show the medicalisation of childbearing.

The growth of large pharmaceutical companies coexists with increases in the medicalisation of social conditions. Many major pharmaceutical breakthroughs occurred after World War II when large investment companies began funding marketing and research (Burton & Roell, 2003). Medicalisation generates further financial advantage to physicians, pharmaceutical and medical device industries (Heitman, 1999). The US market is the major profit centre for the world's top ten global drug companies because of the higher numbers of FDA-approved drugs compared with other advanced countries (Angell, 2004). In the USA in 2005 it was estimated that the cost of medicalisation (4% of USA national health expenditure) was greater than the spending on public health (3%) (Budetti, 2008; Conrad, 2010).

Pharmaceutical companies play a central role in the definition of disease and categorisation of illness. High expectations of a drug increase its market share (Moynihan, 1998). Australian law prohibits direct advertising of prescription drugs to the public. To overcome this limitation, pharmaceutical companies provide grants to independent disease foundations that work in close collaboration with drug companies. Medical foundations and support groups receive sponsorships from pharmaceutical companies to advertise disease awareness campaigns while inclusively promoting awareness of a medical condition and the company's advertising of the relevant pharmaceutical for that condition (Moynihan, 1998). Australian medical educators hold concerns for medical students being influenced with pharmaceutical industry gifts and hospitality, impacting on future prescribing practices, despite such inducements being illegal (Rogers, Mansfield, Braunack-Mayer, & Jureidini, 2004). The marketing departments of major pharmaceutical companies underwrite disease-awareness campaigns to the public about medical conditions (Moynihan & Henry, 2006). As public awareness grows from the advocacy, patients ask their doctors to prescribe the company's drug. The promotion of a condition in this way legitimises the condition and treatment requirement.

Medical professionals have societal status through membership in a respected profession, which is influential on health policy, and medical practitioners have jurisdiction of the categorisation of medical conditions (Freidson, 1970; Friedson, 1970; Riessman, 1983). However, the autonomous nature of the medical profession has declined in the past 50 years while the power of the major pharmaceutical companies has grown (Greene, 2007). Zola (1972) suggests that the medicalisation of society also fulfils society's faith in the effectiveness of medicine. It is the public's faith in and expectations of medicine that makes possible the opportunity for the commodification of medicine by disease mongering.

### **2.3 Disease Mongering**

Within this chapter, the definitions of medicalisation and disease mongering have some overlap. Medicalisation is a non-judgemental term that implies that a condition is given a medical name, whereas disease mongering suggests a deliberate move to frame a condition in a medical framework for the purposes of financial gain (Williams, Seale, Boden, Lowe, & Steinberg, 2008). Disease mongering demonstrates the widening of the boundaries of treatable illness to increase the range of treatable conditions (Moynihan & Henry, 2006) and the escalation of anxiety about future ill-health in healthy individuals (Mintzes, 2006). Payer (1992) originally defined disease mongering as convincing people who are well or asymptomatic that they have a medical condition of concern by widening of the boundaries of illness, and doctors and pharmaceutical companies use patients for financial gain. Doust (2013) uses the term overdiagnosis for conditions that would never cause harm, and thus exposes the patient to treatments where the benefits may not outweigh the harm of treatment. Moynihan, Heath and Henry (2002), describe disease mongering as a widening of the boundaries of treatable illness in order to expand markets for those who sell and deliver treatments and treating personal problems as medical concerns and seeing risk as disease. Disease mongering can be considered as an aggressive by-product of medicalisation.

Woloshin and Schwartz (2006) suggest the definition of health has narrowed. Disease mongering may be fuelled by the need of corporations to fund drug research to satisfy shareholders by promoting the need for new drugs (Cassels, 2007). Pharmaceutical companies monger potential new markets by extending the definition of disease and illness (Goldacre, 2009; Moynihan, 1998). Pharmaceutical companies in the USA use a direct marketing process that encourages patients to discuss new products with their clinician with the potential to pressure clinicians to prescribe that drug (Applebaum, 2006).

Moynihan (2006) and others, suggest that disease mongering presents a global challenge in the public health area by increasing the marketing potential of pharmaceuticals that promote treatment (Collyer, 1999; Mintzes, 2006; Moynihan et al., 2002; Shankar & Subish, 2007). Moynihan suggests, for example, that lowering of the normal range of blood pressure is not a public health issue but a move by pharmaceutical companies to increase their market share of blood pressure lowering drugs (Australian Institute of Health and Welfare, 2011; Moynihan, 2010). Consequently, deviations from this norm are perceived as disease and pre-symptomatic conditions are medicalised.

The marketing of Viagra by Pfizer for either medical or social erectile dysfunction demonstrates how drug companies have identified so called lifestyle drugs, as a growth market (Lexchin, 2006). Men initially used Viagra to alleviate erectile dysfunction caused by injury, diabetes or prostate surgery. Pfizer used carefully reported statistical research to construct a perception that many men have erectile problems and Viagra enhances sexual performance. In this way, companies can identify a lifestyle market for pharmaceuticals for non-life threatening but life-enhancing conditions (Lexchin, 2006).

Pharmaceutical companies encourage disease mongering by sponsoring medical conferences and selecting medical practitioners as product promoters or key presenters. The pharmaceutical company Organon, part of Schering-Plough/Merck, manufactures drugs used for infertility treatment and sponsors reproductive medicine conferences. Platinum-level sponsors at conferences can recommend key speakers or themes to promote their product in Australia (Moynihan, 2008). According to a past president of the Australian Medical Association (Hambleton, 2012) in 2012, pharmaceutical companies spent \$30 million wining and dining doctors and allied health professionals at educational sessions for marketing purposes. Such an alliance assists pharmaceutical companies to market their products and presents an ethical dilemma for medical clinicians who face a duality of interest between incentives and clinical practice (Australian Institute of Health and Welfare, 2011; Moynihan, 1998). Dualities of interest need to be publically declared and apparently transparent to patients within the clinical setting (Komesaroff & Kerridge, 2002).

## **2.4 The Medicalisation Of Infertility**

It is generally accepted that infertility is understood by the community to be a medical condition. However, infertility does not have to be cured, as it has no detrimental effects on wellbeing other than limiting the ability to have children. Infertility can remain undetected

until trying to conceive, and then infertility becomes an illness only by the virtue of one symptom, which is lack of a desired child (Sandelowski et al., 1990). Within the Australian context, infertility is seen as a medical condition requiring medical resources.

Women's lives are increasingly becoming medicalised particularly in the areas of reproduction, childbirth, menopause, and fertility (Inhorn, 2006). ART has medicalised conception (Smajdor, 2011). Healthy women who are struggling to conceive become patients within a medical environment in which human reproduction is the goal (Ferguson & Ragone, 1997:68). The medicalisation of infertility began in the 1960s with the introduction of fertility drugs such as clomiphene citrate (Clomid) (Glud, Kjaer, Troisi, & Brinton, 1998; Greil, 1991a). The use of ART for single women, same sex couples and women with age-related infertility demonstrates a social use of medical technology rather than for medical necessity (Conrad, 2004) because infertility is not considered a medical issue rather a "social fact based on marital and maternity norms in our society" (Roach, 1988:164). Heitman (1999) suggests that IVF has itself contributed to the medicalisation of infertility and the imperative nature of ART despite its uncertain success rates.

The social construction of infertility is based on the biomedical model, which creates a paradigm of normal childbearing and where deviations from the norm are considered abnormal. Barker (1998) suggests this normal–abnormal dichotomy legitimises diagnosis and medical treatment behaviour. Such a model is perpetuated in the popular press with midlife intending mothers seeking treatment for subfertility (Australian Institute of Health and Welfare, 2011; Becker & Nachtigall, 1994; Sandelowski, 1991; Woollett, 1996). Midlife intending mothers can become medicalised when their reason for attending a clinic is for medical assistance; as the cause of some infertility is socially constructed such as postponement of childbearing (Collyer, 1999; Van Balen, 2009).

Infertility clinics found a ready market among educated women who can afford ART treatment to alleviate age-related infertility (Heitman, 1999). The concept of infertility as a social problem is being challenged in some states of the USA, where consumers have mounted legal action against medical insurance providers who classified infertility as a disability and denied insurance coverage for ART, which constitutes discrimination under the *Americans with Disabilities Act of 1990* (Conrad, 2004; Gilbert, 1996:44). Insurance companies counterclaimed that being unable to conceive is not a disease and ART treatment is elective and insurance covers only the small number of cases of medical infertility rather than social infertility (Conrad, 2004). In comparison, the Australian health



system does not discriminate between a medical or social cause of infertility for public or private health funding.

Individuals unable to conceive can gain public recognition of the importance of the condition by grouping with people similarly afflicted. Medical consumers join support groups whose collective action medicalise conditions such as infertility, as individuals are eager for medical categorisation. Access Australia is an Australian infertility consumer support group associated with infertility clinics and lobbies on behalf of consumers for improvements to ART funding.

Spiralling needs, expectations of technology and promises of technology are balanced against the increasing cost of the technology and the ability of health budgets to afford technology against limited health funding (More & More, 1994). However there are limitations to the capabilities of ART technology (Williams & Calnan, 1996b). Bhattacharya (2001:2078) suggests “assisted reproduction has been technologically driven rather than evidence based” and “treatment tends to be empirical, and existing evidence can be ignored for novel interventions”. Women may be vulnerable to unrealistic expectations of the technology during infertility treatment as they may not have the knowledge necessary to challenge the authority or decisions of their clinician regarding their care (Lupton, 1997). It is concerning that a misunderstanding of the age of fertility decline also exists amongst general medical practitioners who are the primary health contact for women (MacDougall, Beyene, & Nachtigal, 2013; Qu & Weston, 2005; Weston & Qu, 2005). Disease mongering may permit the perception that ART is likened to a safety net, which allows some women to believe that medical technology can bypass age-related limitations on fertility. However, diminished oocyte quality and quantity in midlife intending mothers cannot be reversed and ART should not be perceived as a fall-back option for women as it cannot guarantee a baby (MacDougall et al., 2013; Qu & Weston, 2005; Weston & Qu, 2005).

Medicalisation may give authority to sections of the medical industry that seek to promote a particular agenda or to promote a financially lucrative industry such as infertility clinics and pharmaceuticals (Chambers & Sullivan, 2005; Williams, 2008). Kovacs proposed in the *Medical Journal of Australia* that the Australian public favours Medicare funding for ART; however, the author is an infertility clinician with shareholdings in an infertility clinic (Kovacs, Morgan, Wood, Forbes, & Howlett, 2003).

The rush to use ART may be interpreted as medicalisation. In a study of 7,280 Australian women enrolled in the Australian Longitudinal Study on Women’s Health (ALSWH), born

between 1973 and 1978, 18.6% of participants reported a history of infertility. The aetiology of the infertility was not part of the study. Of the 1,376 women reporting a history of infertility, 574 women had used ART. 43.8% of women aged 28–36 years were classed as infertile and achieved a spontaneous conception. The research contrasted treated women with untreated women, and suggests that more than 40% of women aged 28-36 years who were unable to conceive could achieve a live birth in time. Rushing to ART could be perceived as over-servicing as many women may take longer than 12 months of timed and unprotected intercourse to achieve a conception and may not fall into the strict guidelines of infertility (Herbert et al., 2012).

A conflict of interest can exist between prescribing medical practitioners and large pharmaceutical companies regarding the marketing of a disease or treatment in the context of drugs used in Australian ART procedures. Padamsee (2011) established a link between Organon International and clinicians through an industry-produced quarterly magazine ORGYN. Published for fourteen years, ORGYN was distributed to 120,000 obstetricians and gynaecologists and promotes Organon's women's health drugs in an easy-to-read format that describes Organon and clinicians working together in women's reproductive health. ORGYN covered infertility articles with 95.9% of issues thematically framing age-related infertility as a disease. ORGYN portrayed a paternalistic account of the doctor-patient relationship, rewarding clinicians for using ART and depicting women as voiceless and passive objects of medical care (Padamsee, 2011). ORGYN illustrates the efforts taken by pharmaceutical companies to shape clinicians' views and prescribing behaviour for reproductive issues.

Infertility clinics medicalise by promoting social oocyte freezing with financial benefits for themselves and pharmaceutical companies (Heitman, 2002). Oocyte freezing as a growing market contributes to the medicalisation of infertility (Mohapatra, 2014). Evers (2013) suggests that introducing new infertility treatments without proper empirical evidence of benefit is an ethical issue because subfertile couples are open to exploitation. Robert Winston believes that women are being deceived, as by the time women aged 36 or older worry about their fertility it is too late to cryopreserve oocytes (Cohen, 2015). Cohen attended an Australian clinic information session on oocyte freezing and found the marketing information misleading. Clinicians did not discuss age-related birth rate predictions. Women were advised that they should preserve 10 oocytes to have a reasonable chance of pregnancy, costing around \$10,000 per cycle. However, older

women would be unlikely to obtain 10 viable oocytes in one cycle and need to preserve at least 15–20 oocytes, as the chance of a pregnancy per oocyte is 5–7% (Cohen, 2015). Oocyte preservation is financially lucrative as clinics charge for freezing cycles, storage, and IVF cycles to use the oocytes in the future.

## **2.5 Commodification In Medicine**

Commodification is the transformation of goods and services (or things that may not normally be regarded as property or services) into a commodity (Parrott, 2014; Polanyi, 2004). Commodification exhibits certain key features: every commodity has a price, commodities are interchangeable with other goods of similar quality, and their value is measured by their ability to satisfy the owner's desires (Kaveny, 1999). Health care can also be commodified where there is a cost to an individual for health services. If healthcare is to be considered a commodity, then it can be sold in the marketplace (as with other commodities) and it is desirable to create a demand for that product. Plato refers to doctors as 'true physicians when they are healers first and money-makers second' (Pellegrino, 1999). In the context of medicine, commodification occurs when a new disease or disorder is promoted to create markets for a new pharmaceutical regime.

Medicalisation and commodification of new medical conditions are demonstrated by descriptions of prehypertension and prediabetes. Prehypertension describes individuals with blood pressure readings on the upper limit of the normal range, and prediabetic where the lower level for glucose intolerance is reduced. By altering the normal range of a condition, a new population is exposed and can be considered at possible risk for a medical condition, which may not develop but medication will be prescribed (Moynihan, 2010: 484.). Side effects from medication for these conditions may do more harm than good, as individuals may not develop these conditions, and individuals could adopt a healthier lifestyle as a drug-free alternative (Greene, 2007). Changes to clinical thresholds may unnecessarily burden society in exchange for limited value to individuals and develop new markets for pharmaceutical companies (Yudkin & Montori, 2014).

Clinicians in the UK and in the USA are being offered consultancy and sponsorship payments to recommend pharmaceutical products which Dyer (2014) suggests, is a conflict of interest and threatens the integrity of the medical profession and the quality of patient care. In the USA, between 2009 and 2012, there were US\$4 billion dollars dispersed to health professionals by 17 pharmaceutical companies and their subsidiaries,

with details of the disclosure required by the Physician Payment Sunshine Act, a part of the 2010 Affordable Care Act. Genetech, Incorporated dispersed US\$388 million dollars to 1,892 doctors in that period (Sagara, Ornstein, Grochowski, & Merrill, 2013). Similarly, in the UK in 2013, £38.5 million was paid to 21,000 clinicians and healthcare professionals (Dyer, 2014). Since 2015, the ACCC requires Medicines Australia to report transfers of value such as speaking fees, advisory board fees, or sponsorships for conference attendance to ensure transparency in areas of possible conflict of interest (Australian Competition and Consumer Commission, 2015). Commodification also extends to the ART industry.

## **2.6 Commodification Of Infertility**

Reproducers become consumers when they use bought services and goods such as ART to conceive and consume these services to become parents (Fletcher, 2006).

Commodification has been described as "...not only the actual buying and selling, but also market rhetoric, the practice of thinking about interaction as if they were sale transactions" (Radin, 1987). Radin's definition encompasses ART and other healthcare where, in principle, everything is a commodity because products are traded for money. Madeira (2015) argues from a legal and ethical perspective that ART is commodified. It is the normalising of ART practices that make commodification possible for gamete and embryo donation, surrogacy and ART (Widdows, 2009). The commodification of ART is not openly discussed in the media or medical field.

Decisions on the timing of parenthood can be attributed to a lifestyle decision. Many aspects of motherhood or parenthood are commodified, including surrogacy and adoption. As ART becomes more of an acceptable social phenomenon, motherhood is becoming commodified. There are many commodities to trade in ART, as clearly the primary commodity for women is a baby and childbearing is a commodity to be targeted by "the new reproductive marketing" (Rothman, 2000). Patients have become consumers, and eggs, sperm and embryos have become commodities (van Dyck, 1995). Infertility clinics sell time mitigation, while medical, personal, and pharmaceutical interests drive ART as a commodity (Shanahan, 2012). The discussion surrounding the medical ethics of ART has shifted to a discussion of ART as a technology with power, commodification, and commercialisation implications (Dyson, 1995; Madiera, 2015). Infertility clinics' marketing and advertising campaigns appear to promote commodification.

The costs of ART procedures are steadily increasing. The Australian ART pioneer, Professor Alan Trounson, suggests that the cost of ART does not reflect the outlay by clinics or specialists but the supply and demand of a commodity. He suggests that ART treatment could cost hundreds not thousands of dollars, but clinics do not want to charge less because the treatment costs are lucrative. They charge what the market will tolerate (Medew, 2014). From 2000 to 2005, Medicare released \$584.6 million dollars for ART services and saw the costs to the Medical Benefits Scheme (MBS) rise from \$50 million in 2003 rising to \$108.4 million in 2005 (Assisted Reproductive Technologies Review Committee, 2007; Dunlevy, 2007; Smith, 2006) and to \$251.6 million in 2013–2014 fiscal year (Australian Government Department of Human Services, 2014). In the 2013–2014 financial years, of the 24,934 Medicare rebateable services for ART, 14,489 were for women aged 35–44 years of age (Australian Government Department of Human Services, 2014).

The Extended Medicare Safety Net (EMSN) was introduced in March 2004 and designed to provide additional financial assistance for patient's out-of-pocket costs when undertaking out-of-hospital services. It was designed to pay 80% of the out-of-pocket costs once the individual's or family's threshold had been reached. When introduced in 2004, the lower threshold was \$300 for Commonwealth concession cardholders and for those who qualified for the Family Benefit Part A payment, the general threshold was \$700 for families and individuals. In 2007, the EMSN distributed \$324 million dollars to 790,000 Australians (Savage & van Gool, 2009)

Clinicians can independently increase the gap payment between the Medicare rebate and their fee. The Review report showed that for some services, such as obstetrics and ART, the EMSN had been used by specialist doctors to raise their fees, aware that the taxpayer would cover 80% of the fee rise. The EMSN benefit was intended to be a patient benefit; it was not intended to be a mechanism for doctors to increase their fees (Australian Government Department of Health and Aging, 2014). The Department of Health and Aging claimed that infertility clinics did not increase fees for relevant Medicare items 13200 and 13209 while the Independent Review of Assisted Reproductive services was underway between 2005 and 2006. Then the average fee increased dramatically. As providers gained 52 cents and patients gained 48 cents of every dollar spent in the EMSN in 2008 (Savage & van Gool, 2009) it was beneficial for the clinics to increase their fees and encourage patients to undertake multiple cycles

From 2004 to 2007 the EMSN funding of ART increased from \$29 million to \$72 million (Savage & van Gool, 2009). Following the introduction of the EMSN, infertility clinics increased fees for a stimulated cycle from \$3269 to \$4089 per cycle (Metherell, 2005). The government quoted figures for Medicare rebates for three stimulated cycles rising from \$5,000 in 2003 to \$10,000 in 2004 (Australian Broadcasting Corporation, 2005). In 2006, benefits for ART from 68 private infertility clinics comprised 22% of all benefits paid by the EMSN (Chambers, Hoang, Zhu, & Illingworth, 2012a). General practitioner consultations accounted for 40.7% of Medicare rebates and received 14.2% of total Medicare funding. However, ART comprised only 0.05% of Medicare rebate services and received 12.7% of total Medicare funding (van Gool et al., 2009). Changes to out-of-pocket fees were implemented in 2010 to rationalise EMSN's spending on ART, which was estimated to provide savings of \$69.4M annually but saved \$84.2 M (Chambers et al., 2012a; Chambers, Van Phong, Zhu, & Illingworth, 2012b; Robotham, 2010). The changes resulted in a significant decline in the number of women having IVF cycles in particular among women 40 years or older (Chambers et al., 2012a). The 21–25% decrease in the number of women of all ages accessing IVF suggests that the additional out-of-pocket expense of approximately \$2500 was financially prohibitive for many couples (Chambers, Hoang, & Illingworth, 2013b).

In 2005, the government increased the out-of-pocket threshold expenditure and proposed a stimulated cycle limit of three cycles in a calendar year for women aged younger than 42 years, and a total of three cycles in a lifetime for women aged over 42 (Dunlevy, 2007). The public outcry was so vehement that the proposal was dropped from the budget (Peatling, 2005). Lobbying by stakeholders from infertility clinics continues to advocate for increased Medicare funding for ART services. Professor Stephen Leeder of the Menzies Centre for Health Policy suggests that the government's rational argument to limit public funding to older women accessing ART was difficult as ART is "protected territory" and both politically and ethically sensitive (Nogrady, 2008)

Australian infertility clinics are a lucrative health sector business with fiscal growth up to 10% annually (Thompson & Connors, 2011). Private equity fund managers predict that the \$500 million a year ART industry will double in a few years because of the increase in social infertility (Medew & Baker, 2013b). The cost for a single fresh IVF cycle has increased by 18% from 2007 to 2012, which is three to four times the rate of health service inflation (Medew & Baker, 2013a). Interest in the ART industry includes; pharmaceutical companies, professional medical associations, and venture capital companies which

control the majority of infertility clinics in Australia (McCullough, 2010), international sperm banks that supply semen to Australian clinics (Becker, 2000), and independent Australian clinics. ABN AMRO purchased 53% of Monash IVF in 2007 which valued the group at \$200 million, and Quadrant Private Equity paid \$32.6 million for 10.9 million shares in IVF Australia (Nogrady, 2008). Virtus Health owns three of the most successful ART companies in Australia with estimated earnings of \$50 million in 2010 and half yearly revenues in 2014 of \$101 million. These companies acquire over half their income from Medicare rebates (Manning, 2014; Thompson & Connors, 2011), and their net profit for 2013/2014 increased 17.2% to \$32 million (Gardner, 2014a) (Gardner, 2014c). Virtus justified the corporatisation of infertility clinics claiming the provision of secure finances funds research and hence better patient outcomes. However, some patients claim they have not seen any noticeable improvement in services between 2007 and 2012 (Medew & Baker, 2013a 2012). Clinicians are reported to hold 20% of Virtus and Monash IVF stock listed on the Australian stock market and valued at over \$1 billion (Dingle, 2014).

Professor Geoff Driscoll, believes that prices in Australia will remain high because of the lack of competition between private equity groups who manage the major IVF groups. There is also no economic incentive to offer less costly treatments (Stark, 2011). Driscoll, who is on the board of the Low Cost IVF Foundation which aims to deliver affordable but effective ART to developing countries, claims that low cost IVF is not of interest to Australian ART clinics (Low Cost IVF Foundation, 2011). Virtus introduced a low cost subsidiary clinic for basic cycles with minimum out-of-pocket fees, and a low cost clinic operated by Primary Health has slashed the out-of-pocket expense from approximately \$4000 to \$500 per cycle (Gardner, 2014 a,b).

Private lobbying endeavours to obtain Medicare rebates for new ART techniques are demonstrated in the infertility clinics' campaign to receive a Medicare rebate for ICSI. ICSI involves injecting a single sperm into an oocyte to assist fertilisation. In 2004, ICSI was used over 12,000 times in Australia and New Zealand with Medicare rebates totalling around \$4 million (Robotham, 2007). In 2007, a Medicare rebate of \$380 per service was approved (Commonwealth of Australia, 2008), based on a capital cost of equipment, labour, and consumables. The rebate was estimated to cost \$31 million per year based on the 1999 figures of 8,000 cycles per annum as clinics claimed that 8% of cycles would use ICSI (Commonwealth of Australia, 2008 :74; Wang, Chambers, & Sullivan, 2008a, 2010; Yudkin & Montori, 2014). After Medicare approval, in 2006, ICSI usage increased to almost 25,000 cycles and then to 32,800 cycles in 2010. In 2010, 67.3% of autologous

cycles used ICSI (Macaldowie, Wang, Chambers, & Sullivan, 2010). It is unclear if increased ICSI use reflects patient demand, decreased semen parameters, clinics wishing to boost conception rates, or a misconception allowing the Medicare rebate.

Prior to the May 2009 budget the government reviewed Medicare rebates for ART with the out-of-pocket payment at around \$3,000 (Dunlevy, 2009b). Proposed reductions to the EMSN would reimburse \$257.9 million dollars. ART clinics had increased their fees, on average, by 290% when the EMSN was initiated (Australian Government Department of Health and Aging, 2009; Dunlevy, 2009b). A clinic director claimed there was a three-fold increase in cycles before the funding cuts to the EMSN before 1 January 2011 (Dunlevy, 2009a). Dunlevy noted that obstetricians (many obstetricians also practice ART) in 2009 increased their fees by 20% compared to 5% in other specialities. Changes to the EMSN for ART in January in 2010 doubled the out-of-pocket expenses to \$2,000 per stimulated cycle by reducing the number of cycles undertaken (Robotham, 2010). An ART clinician stated, “the thought of people not being able to achieve their dream of having a baby because of Medicare changes is saddening” (Wilkinson, 2010). Excessive increases in ART fees resulted the government reducing EMSN benefits (Wilkinson, 2010). Reductions to funding was opposed by clinics and Access Australia, which is partially financed by infertility clinics, and a concerted campaign against these changes was initiated emotively claiming that women would not be able to afford to have children as a consequence.

Midlife intending mothers have a lower probability of conceiving than younger women but are the greatest consumers of ART services. Increasing numbers of older women accessing ART has seen the Medicare benefits for procedures double since the 2004 estimates, with \$11 million paid for ART for women aged 40 years and older (Chandler, 2005). Westmead Fertility’s clinic manager stated that women aged over 43 years accessing ART had a “slim, slim chance” and “you are wasting your time and money to be totally realistic, and you are just stringing them [older female patients] along, giving them false hopes” (Bissett, 2008). Federal Treasurer Peter Costello stated “there is no point in giving treatments where there is a very, very low chance of success” (Chandler, 2005). Terry Barnes, a former health adviser to the Howard government, suggests that it is appropriate for the government as a subsidiser of ART to place limitations on the number of attempts that can be made (Dingle, 2014). Barnes suggested that the two companies that provide 80% of the ART services are listed on the ASX with a combined value of more than \$1 billion, and 20% of their shareholders who are doctors and fertility specialists who directly profit from each ART procedure. Skekette (2005) writes that the aging of the



society and the increased demand for medical technology places pressure on governments to evaluate the cost-effectiveness of individual medical procedures and techniques.

Costs for ART are both direct and indirect. Direct costs include medical consultations, pathology and laboratory testing, and hospital and treatment procedures. Indirect costs are costs arising from complications of ART procedures, disruption to employment and costs of multiple births (Chambers, Adamson, & Eijkemans, 2013a). One of the few economic appraisals of individual costs for ART demonstrates the greater fiscal costing for an older, compared with a younger, woman to have a baby. Women attending infertility clinics aged less than 30 years spent an average of \$24,809 on ART per birth compared with women aged 42 or older who spend \$97,884. If a woman aged 42 is fortunate to have a child after ART, she will have spent on average \$182,000 for that conception (Chambers & Sullivan, 2005). Analysis of ANZARD data between 2002 and 2004 concluded the success rate for a live birth for women aged 45 and older, was less than 1% and the cost of each baby was more than \$500,000 (Sullivan, Wang, Chapman, & Chambers, 2008). These economic data question the increasing negative cost-effectiveness of Medicare rebates for ART for women over the age of 35 years.

There is no legal requirement for fertility specialists holding shares in the company to disclose to their patients their shareholding, which could be viewed as a conflict of interest. Full disclosure of a clinician's commercial interests in infertility clinics should be provided to patients in light of possible influence by commercial interests (Coombes, 2014), particularly as most infertility clinics offer in-house pathology services that patients are required to use. Professor Robert Norman, a non-shareholding consultant to the Repromed clinic in South Australia, suggests that shareholding clinicians are guided by their governing venture capital company and may steer patients quickly into the high-cost IVF route rather than initiating low-intervention options (Gardner, 2014a, 2014c). Professor Seamark (Australian Broadcasting Corporation, 2014) expressed concern that profits from clinics that previously were for clinical research now were returned to shareholders. Associate Professor Beverley Vollenhoven commented that one of the main providers of ART was inflating success rates, reducing scientific research, and not consultative on staffing and treatment price increases (Cohen, 2015) and the clinic seemed to be moving from its core values (Whyte, 2015).

Demand for a commodity is achieved by increasing the awareness of the product. The Australian Medical Association does not favour the direct advertising of medical or infertility services because this may be perceived as persuasive or may exploit patient's vulnerability or lack of medical knowledge (Australian Medical Association, 2006). Advertising blankets with narratives and signifies the position and the meaning of the commodity (ART) within non-commodified relations such as the images of a happy family. News articles can sensitise audiences with depictions of cutting-edge fertility treatments, and these visual images, when combined with ART success stories, can be persuasive (van Dyck, 1995). Van Dyck suggests the process of commodification of ART is achieved by telling a positive story to allow justification of the time, expenses, and efforts to use the technology. It is important that businesses marketing a positive ART story do not sell false hope by claiming success rates higher than those from accredited data such as ANZARD (Australian Broadcasting Corporation, 2014). Widdows (2009) suggests the "cute factor" of a new baby and the willingness of users of ART to accept the health, psychological, and medical risks of the technology overrides concerns.

There exists a close relationship between the pharmaceutical companies who manufacture ART drugs and infertility clinics. The marketing practices of drug companies have an effect on clinicians' prescribing behaviour, despite a belief to the contrary that inducements have no effect. This may arise because of the conscious or unconscious behaviour of indebtedness after an inducement (Orlowski & Wateska, 1992). Pharmaceuticals used for ART ensure large profits. In 2011, worldwide sales of Gonal-F, a recombinant hormone for ART, rose 7.2% to €130 million due to a high demand in Australia, Asia and Africa (Merck, 2011). Pharmaceutical companies sponsor medical conferences focused on women's health and infertility. They also sponsor clinicians' attendance and speakers to these events, as they have a vested interest in the business of ART (Health, 2006). Benefits are offered as an incentive to use a product over the similar products of opposition companies even if there is parity between the costs of the products.

Initially, Medicare covered a lifetime funding of six stimulated cycles per woman as it was postulated that 90% of women would conceive within four or fewer stimulated cycles. After six cycles, women had to fund the treatment costs themselves (Kovacs et al., 2003; Smith, 2006). The six-cycle limit was abolished in 1999 due to public and clinic pressure with clinics defending the abolition when 1.5% of women went beyond six cycles (Cummings, 2005). Governments are concerned about rising health expenditure and its sustainability (van Gool et al., 2009). Medicare partially funds Australian citizens having ART but the

out-of-pocket expenses discriminate against women in low-socioeconomic groups who may find these costs prohibitive. This represents inequality in the Australian health system. Evaluating the cost-effectiveness of medical treatments is a challenge when health is a rising expenditure for governments (Mastenbroek & Repping, 2014).

## **2.7 Technology Mongering**

Hoffman (2006) suggests that technology has become a symbol of our culture. Humans, market forces and consumer requirements socially shape medical technology (MacKenzie & Wajcman, 1999). Technological imperative is created, as once a technology is underway, it is unstoppable and progress is inevitable (Hofmann, 2002). As when technology is introduced into a culture, what follows is the inevitable use of technology, which leads to further technological developments (Fuchs, 1968). Technology mongering describes the phenomenon by which individuals are influenced or compelled to use procedures that may be optional or experimental and may have unsubstantiated benefits. Innovations in medical technology present ethical dilemmas and challenge the boundary between health and illness (Lauritzen & Hyden, 2007). When ART was developed, it created a need that exceeded the initial indications of the technology, as the human action has shaped the continual development of technology (Heitman, 1999; MacKenzie & Wajcman, 1999).

ART has become socially acceptable because people believe in medical technology as a symbol of our culture and progress (Hofmann, 2002). Australians have a high level of confidence in scientists, scientific institutions, and biological technologies (Farquharson & Critchley, 2004). ART embraces new technology - such as ICSI, preimplantation genetic diagnosis (PGD), preimplantation genetic screening (PGS), comparative genomic hybridisation (CGH), and oocyte freezing. The confidence in technology and its ability to achieve high success rates is often not comparable to published success rates. Women may feel that there is technological imperative to use new medical technology (Motluk, 2011), as many women are eager to try new technology to have a child despite its effectiveness being unproven.

Steures et al (2006), in a study of 253 couples, suggests that the use of technology should be evaluated for couples using ART, and that selection of couples best suited for insemination cycles be qualified. This eliminates the unnecessary use of technology and resources. A study of 9818 couples attending Dutch infertility clinics for idiopathic infertility suggested that overtreatment occurred in 36% of the participants, possibly exposing them

to unnecessary treatment (Kersten et al., 2015b). Some clinics promote success rates of 30% to 40%, but some are as low as 8 to 15% (Hinde & Vogler, 2008). Hinde and Vogler (2008) claim that some clinics “massage” their marketing information for ART success rate by reporting pregnancies rather than a live births. Reporting early stage clinical pregnancy rates elevates the reported success rate when 10% of these pregnancies may not be viable or may not proceed to birth. Technology mongering can increase women’s expectations of achievement when clinics advertise success rates for younger women who have higher pregnancy and birth rates, rather than midlife intending mothers, who have lower success rates.

The national infertility support organisation Access Australia, has a pharmaceutical supplier of ovulation drugs as a patron (\$40,000 annually), and two infertility clinics which provided \$20,000 and \$10,000, respectively for annual support (<http://www.access.org.au>)(Michelle, 2007). In defence, Healy (2004) suggests that pharmaceutical companies support consumer patient groups as part of an intentional marketing strategy to lobby government assistance for increases to the PBS. As a consumer advocate group, Access Australia has been an energetic campaigner for Medicare rebate funding to remove the six funded-cycle limitations and the funding of ICSI by Medicare. Access Australia cannot objectively lobby for consumers due to its vested interests.

A specific example of technology mongering in ART is the use of PGD or PGS, which is available in many Australian ART clinics. PGS can be used to screen embryos for chromosome aneuploidy (an embryonic chromosome imbalance with loss or gain of a whole or part of a chromosome). The American Society of Reproductive Medicine (ASRM) does not support PGS for common aneuploidy screening in older women or support that PGS leads to improved live-birth rates in women of advanced maternal age, (American Society for Reproductive Medicine, 2007; Medicine, 2008). Mastenbroek and Repping (Mastenbroek & Repping, 2014) suggest that clinicians who offer PGS are either unaware of such data or driven by other motives, as PGS is financially lucrative for infertility clinics. In some centres, PGS has been found to reduce rather than increase the chance of a successful pregnancy due to the potential of loss of the embryo after manipulation to remove a single cell for testing (Dondorp & de Wert, 2011).

Zeiler (2004) found that women considering PGS perceived a technological imperative to use it if it is available. Selecting not to use PGS implies they were doing less than they

should to ensure the birth of a healthy child. PGS is promoted as a service than can lessen women's anxiety because it screens out common aneuploidy-affected embryos. Zieler's (2004) interviews indicated that for some women, the choice of PGS increased their trauma and could reduce their ability to make autonomous decisions. Some women perceive that infertility professionals have an unconscious vested financial interest in promoting PGS and alternative technologies, and procedures are not discussed sufficiently with the consumer (Zeiler, 2004).

Some assert that clinics adopt new technologies without clear empirical data on its clinical success and individuals may select clinics which offer breaking technology (Mastenbroek & Repping, 2014). It is the clinician's ultimate decision to use technology that has not undergone clinical trials, despite the patient giving consent. There is a possibility that infertility clinics may adopt or copy new technologies without undertaking research to evaluate clinical studies or the safety of the patient before offering it as a routine procedure (Dondorp & de Wert, 2011).

Currently, science is unable to delay the biological aging of oocytes. Some midlife intending mothers are unable to conceive with their oocytes and require donated oocytes from younger women as their only chance of a pregnancy (Tarlantzis & Zepridis, 2003). Technology mongering is evident when clinics promote the concept of younger women taking out reproductive insurance by freezing oocytes if they wish to delay childbearing to an age when their fertility potential is compromised (Shkedi-Rafid & Hashiloni-Dolev, 2011). Data for the success rate of oocyte preservation does not support marketing claims. Robert Winston (Cohen, 2015) suggests women are being given false hope of success as the IVF industry preys on the anxieties of women. Despite recent technological improvements, the implantation rate is 13.2% for women younger than 30 years reducing to 8.6% for women aged 40 years of age (Cil, Bang, & Oktay, 2013). Mohapatra (2014) suggests that the medicalisation of women's reproduction, because of social constraints to have a child when younger, is ill advised. Oocyte freezing puts young women through ART oocyte collection cycles that carry potential medical risks. Future use of preserved oocytes is via ART with ongoing storage fees and treatment costs and with no guarantee of success.

Woloshin (2006) suggests that the media overstates the benefit of IVF technology by telling stories of dramatic benefit and by minimising potential harms. Dr. Peter Illingworth, a clinician from IVF Australia, stated that "there's a lot of emotional attachment to this

piece of frozen tissue, and six or seven years later it's going to be a blow when it doesn't thaw out" (Nowak, 2007). Women may have unjustified optimism and limited knowledge regarding the success of oocyte preservation and, hence, be open to technology mongering (Harwood, 2009). As McLeod (2002) suggests, women believe they are buying insurance against age-related infertility but may be inadequately informed of the possibility of preserved oocyte cycles failing when required in the future. Lord Robert Winston suggests that egg freezing is a "confidence trick" with fewer than ten percent of women who use their frozen eggs conceiving (Francis, 2014; McLaren, 2014), and over a five year period in the UK, data showed that each oocyte had a 1.5% of progressing to a birth (Cohen, 2015). Professor Gab Kovacs said "women should not be conned into thinking it offered a guaranteed family in the fridge" (Medew, 2011). Martin (2010) suggests this technology creates a new reality of anticipated infertility with healthy fertile women anticipating they will need ART in the future.

Oocyte freezing for social reasons does not qualify for a Medicare rebate and each cycle costs approximately \$10,000 out-of-pocket which could be cost prohibitive for women (Lemoine & Ravitsky, 2013). Women may need multiple cycles to harvest sufficient oocytes for future use because each cycle may yield fewer than ten oocytes and no clear guidelines exist to recommend the optimal number to freeze per anticipated child (Baldwin, Culley, Hudson, & Mitchell, 2014). The media uses phrases such as "reproductive insurance policies", "social egg freezing" (Carrington, 2008) and "putting your reproductive future on ice" (Wildman, 2006) to depict this technology when the chances of a birth from stored oocytes are not guaranteed. Some women may wish to store oocytes when aged in their late 30s and 40s, when their fertility is declining (Baldwin et al., 2014). An Australian infertility clinic and companies Apple and Facebook, will subsidise oocyte freezing for its employees and suggest that this will assist women who are "time-trapped" by social factors (Francis, 2014; McLaren, 2014). Lemione and Ravitsky (2013) suggest this does not improve reproductive autonomy but avoids improving workplace conditions to allow women to have children without detriment to their career.

In 2013 the ASRM advised that there was insufficient data to recommend oocyte freezing for the sole purpose of circumventing reproductive aging in otherwise healthy women (American Society for Reproductive Medicine, 2013). In 2009, the Royal College of Obstetricians and Gynaecologists in the UK warned that woman should not look to oocyte freezing for nonmedical reasons (Motluk, 2011). There is no fall-back option for women if their frozen oocytes fail. Oocyte preservation moves ART from a therapy into an elective

social use of technology and into the realm of family planning and reproductive autonomy. Women need to be fully informed of the benefits and the drawbacks of reproductive technology from an independent authority, to ensure they are making the best decision in their circumstance.

## **2.8 Anticipated Decision Regret**

The theory of anticipated decision regret proposes that an individual who wishes to avoid regret about a decision they are currently making may behave in ways to avoid regret (de Zoeten, Tymstra, & Alberta, 1987; Tymstra, 1989, 2007; Zeelenberg, 1999). This theory suggests that women could have their expectations raised about the capability of ART and consequently women may persevere with repeated ART cycles so they do not, in the future; regret the decision they may make to discontinue treatment.

Individuals may have feelings associated with health decisions and then experience emotions more adverse than they initially anticipated. Decisions about health are made in the context of feelings and emotions, whereby individuals are not inclined to refuse to use a diagnostic or a treatment because that decision may be regretted at a later stage (Tymstra, 2007). Avoidance of decision regret is a driving force for women who have repeat ART cycles until they are successful. The avoidance of regret gives medical technology an imperative character (Tymstra, 1989).

De Zoeten (1987) explored anticipated decision regret through a small study in a Dutch infertility clinic. Participants reported optimism that their treatment would be successful and that they would continue with treatment even if their chances of success were 2% because they did not wish to experience regret in the future. As Tymstra (2007) suggests, women should be informed of possible future regret and avoid self-blame for not embracing current medical technology.

Women are postulated to start ART because the technology is available to them and that they may do so in order to avoid anticipated decision regret. Hofmann (2002) suggests that this is influenced by a technological imperative because women believe they have to participate in the most advanced level of technology available. In the developed world, women have the opportunity to access ART and may feel that they cannot refuse to use the available technology (de Zoeten et al., 1987; Sandelowski et al., 1990; Tymstra, 1989). De Lacey (2002) explores a lottery analogy (the next cycle will be a winner) within the Australian context and suggests that infertile women who persist with ART until they

succeed are predominantly represented in the popular media and rewarded for their persistence.

Some couples undertaking ART find the process therapeutic even if the cycles are not successful, as they have tried the technology available to them. Zeiler (2004) suggests that some couples believed they could now relax as they had tried all available options and they did not have to make further decisions on treatment.

## **2.9 Summary**

The use of medical technology, the rise and power of pharmaceutical companies and medicalisation have initiated contemporary debates about health care and, in particular, reproductive technology. Medicalisation is a descriptive term for the intention to take a human character or the extension of a mild human condition to create the impression that it is a medical disease requiring treatment. Some women undertaking ART may not understand that they are consumers of IVF technology and they are being medicalised and potentially commodified.

Some women choose to use ART as they are unable to conceive naturally, and may have unrealistic expectations of the success rate of the technology. Marketing from infertility clinics and pharmaceutical companies portrays the technology as being quite successful, although actual success rates are rarely reported for the largest group, women aged over 35 years, whose success rate is lower. Expectation of treatment success may be elevated by the publication of cumulative success rates, which will be higher than the initiated cycle rate or the live birth rate.

Chapter 3 discusses influences on the childbearing age of women and the factors that influence the decision on the timing of childbearing. Women are tending to have children at a later age than their mothers, and this has implications for their ability to conceive and, if unsuccessful, their reliance on ART as a fall-back option (Gray, Qu, & Weston, 2008).



## **Chapter 3: The changing and contested nature of family in recent times and social factors in influencing women's childbearing intentions**

### **3.1 Overview**

This chapter examines the place of the family in Australia, changes in the structure of families and partnering relationships, and social influences upon women's childbearing intentions. The cost of rearing children with one parental income is offered as a reason for the decline in family size and anticipated family size (Bulatao, 2001). Social, biological and environmental factors such as relationships, career and employment, financial attainment, and educational aspirations shape women's childbearing intentions; these may not always represent a rational voluntary decision (Holton et al., 2011a).

### **3.2 The Family and Childbearing Trends in Australia**

Contemporary Australia reflects changes in the patterns of marriage, partnering, and family formation with stepfamilies, blended families, and sole parent families (Australian Bureau of Statistics, 2008b). Variations in birth rates correspond to social changes, and birth rates vary between developed and developing countries (de Vaus, 2002; Gray et al., 2008). Women's aspirations for the timing and the size of their families are influenced by external factors, which has ramifications on the timing of childbearing (Wang et al., 2008a). Australian parents indicate that economic and career factors, and the embodied experiences of parenthood influence family size and the age of childbearing (Newman, 2004). The size of the family increased during the 1950s because of improvements in the economic climate, a lack of reliable contraception, and a boom in marriages in the post-war period, which led to significant increases in the number of births to young Australian women, peaking at 3.55 births per female in 1961 (Australian Bureau of Statistics, 1994a; Hugo, 2002; Lesthaeghe, 1998; Weston et al., 2004). This was the era of the nuclear family comprising two biological parents and children.

Family size decreased to 2.5 individuals per household in 2006 because of a decline in fertility rates and a change in household structure (de Vaus, 2008; Hugo, 2002). Lee and Gramotnev's (2006) research suggests that most Australian women aged in their 20s plan to have children at some stage. There is an increasing trend for women to have their first

child and further children at a later stage of their life compared to women in previous generations (Wilkie, 1981).

Contraception allows family planning and despite childlessness being more socially acceptable today than then in previous generations, 85% of married couples in developed countries choose to have children (McDaniel & Tepperman, 2000). The availability of female contraception and access to safe induced abortion influenced the timing of childbearing for women in Australia and has contributed to declining birth rates (Frejka & Jean-Paul, 2004; Jain & McDonald, 1997; Weston & Parker, 2002). Initially, mostly educated women embraced the contraceptive pill but, by 1971, it was accepted by women of all social classes (Gilding, 1997).

### **3.3 Maternal Age In Relation To The Decline In Fertility**

There is direct relationship between increasing age and decreasing childbearing potential for women. Females have an optimal time to have a healthy baby. The theory that women have a finite reproductive period was initially posed in 1921 by Pearl (1921: 111) who published the biological doctrine that, “during the lifetime of an individual there neither is nor can be any increase in the number of primary oocytes beyond those originally laid down when the ovary was formed”. Many women’s fertility declines from the age of 35 years (Leridon, 2004) and some researchers suggest fertility declines as early as 32 years of age (American Society of Reproductive Medicine, 2014). Jansen (2003) reported that women aged younger than 34 years require fewer cycles of ART to achieve a pregnancy and had a higher birth rate and lower miscarriage rate than older women. ANZARD data confirms that live birth rate per initiated cycle for ages; 30–34 years was 24.1%, 35-39 years 16.3%, and 40-44 years 5.9% (Macaldowie et al., 2015). Research by Schwartz and Mayaux (1982) and Shenfield (1993) on fertile women’s access to donor semen, support the concept of age-related decline; i.e., women younger than 30 have four times the chance of achieving a pregnancy compared to women aged over 35 years (Klein & Sauer, 2001; Shenfield, Doyle, Valentine, & Ton, 1993).

Menopause, which for most women begins at around age 51 years (range from 40–60 years), occurs when the number and quality of oocytes decreases below a certain threshold and is manifested by the absence of menstruation (Kline, Kinney, Levin, & Warburton, 2000). The menopause occurs 10–12 years after fertility starts to diminish during perimenopause and is the absolute end of fertility (Klein & Sauer, 2001; Tarlatzis &

Zepridis, 2003). The perimenopausal period manifests as a loss of oocyte quality and quantity.

Perimenopause leads to a decline in oocyte numbers; this degeneration in the quality of oocytes has a variable age of onset amongst women (Klein & Sauer, 2001; Lim & Tsakok, 1997) due to varying numbers of oocytes in individuals (Soules et al., 2001). Twin studies shows correlation between age of menarche and menopause within female members of a family, with a heritability of 63% (Snider, MacGregor, & Spector, 1998) and 31–53% (Treloar, Do, & Martin, 1998), respectively. If a woman's mother or twin sister experiences early menopause, she has a higher risk of early menopause (de Bruin, Bovenhuis, van Noord, & Pearson, 2001).

The progression towards menopause can be quantified according to the changes in the endocrine system. The gonadotropin follicle-stimulating hormone (FSH) causes the ovum to mature in the follicular phase, which gives a measurable indication of ovarian aging. As the hypothalamus ages, the FSH level increases, which shortens the menstrual cycle length and results in slower follicular growth, reduced follicle diameter, lower progesterone levels and a transition to menopause (Ebbiary, Lenton, Salt, Ward, & Cooke, 1994; Gosden & Faddy, 1994; teVelde & Pearson, 2002). Measuring the antral follicle count using ovarian ultrasound imaging can assess declining ovarian function. Turfan and Durmusoglu (2004) concluded, there is no abrupt decline in fertility but a gradual decline in the third decade of a woman's life.

Age is a significant factor in oocyte developmental competence. A woman is born with her lifetime complement of six–seven million ovarian follicles. Her ability to have children starts at puberty when fertility peaks with 300,000 to 400,000 follicles, after which atresia decreases the number of follicles each month of a woman's post-pubescent life, which gradually decreases the chances of conception (Cooke & Nelson, 2011) because declining reproductive potential is a continuum (Klein & Sauer, 2001). Atresia is caused by apoptosis when the resting follicle number declines to less than 25,000, which is usually when a woman is aged 37–38 years of age (Hughes, Steingrad, Persson, & Costello, 2005). Once menopause is reached, 1000 or fewer follicles remain, which is an insufficient number to sustain the cyclic hormonal process necessary for conception (Faddy, Gosden, & Gougeon, 1992; Gardner & Sutherland, 2004). Oocyte degeneration proceeds with age and is reflected in age-related chromosomal abnormalities (Lim & Tsakok, 1997).

Oocyte degeneration is confirmed after PGS in IVF cycles (Battaglia, Goodwin, Klein, & Soules, 1996; Gianaroli et al., 1997; Krey et al., 2001). Franasiak et al. (2014) tested over 15,000 trophectoderm biopsies from 2,701 patients in 3,392 cycles to determine by comprehensive chromosomal testing (CCS) to determine if they were euploid or aneuploid. Aneuploidy was lowest in women aged 26–38 years of age, confirming that aneuploidy increases with maternal age. Embryos from women aged 42 years had one-third aneuploid and those aged 44 years had half of their embryos aneuploid. After fertilisation, if the developing embryo has less or more genetic material than required (fewer or more than 46 chromosomes) the embryo will stop developing and miscarry spontaneously or develop until term. If a chromosomally unbalanced embryo continues to birth, the baby may be born with significant physiological or developmental disabilities, and depending on whether monosomy, trisomy, or other chromosomal anomaly is present, this may not be compatible with life. Chromosomally abnormal embryos are responsible for a higher spontaneous abortion rate in older women (Fretts, Schmittiel, Mclean, Usher, & Goldman, 1995; Gardner & Sutherland, 2004; Mueller & Young, 1996). Miscarriage rates for women aged 30–34 years are 12%, rising to 18% for women aged 35–39 years to 34% for women aged 40–44 years. The spontaneous miscarriage rate, for women aged 40 or older, approaches 50% for each pregnancy (American Society for Reproductive Medicine, 2012; Holter, Anderheim, Berg, & Moller, 2006).

Decreased ovarian reserve and age-related changes in oocyte are generally present in women aged 35 years and older, and 90% of spontaneous miscarriages in midlife intending mothers are likely to be caused by trisomies (Kline et al., 2000). An age-related increased risk of trisomies is attributed to age-related errors in meiosis (Kline et al., 2000) related to the decline in the functional competence of the meiotic spindle. These changes cause extra maternal chromosomal material to be present in the embryo (Battaglia et al., 1996). Many trisomic pregnancies spontaneously miscarry during the pregnancy. Trisomies 13 (Patau syndrome), 18 (Edward's syndrome) and 21 (Down syndrome), can progress to birth. From 10 weeks gestation, an estimated 83% of trisomy 13 and 86% of trisomy 18 pregnancies will miscarry spontaneously (Snijders et al., 1995). For trisomy 21, only 31% of pregnancies will miscarry spontaneously (Spencer, 2001). The risk of having a child born with Down syndrome is 1 in 430 births for women aged 34 years, 1 in 84 at age 40 years and 1 in 45 at age of 45 years. Giving birth to a baby with chromosome abnormalities is more common in midlife intending mothers: 1 in 244 at age 34 years, 1 in 64 at age 40 years and 1 in 19 at age 45 years, from the frequently cited research by Hook

(1981). Data for chromosomal abnormalities will reduce due to the uptake of non-invasive prenatal screening in early pregnancy.

Women may be ignorant about their state of fertility. Some believe that as long as they have regular menses they still have ovarian function and can achieve a pregnancy. The study by MacDougall et al. (2013) of 61 American women aged over 40 years found that they did not have a clear understanding of age-related fertility decline. Surprisingly, close to half of participants were shocked to find that their chances of conception were lower than they had anticipated. Research by Hammarberg (2005) concurred with MacDougall's study as 18% of the Australian women in the study were unaware of the link between maternal age and age-related fertility decline. Hammarberg et al. (2013) interviewed 462 childless men and women aged 18–45 years of age on the age of fertility decline and established that one in four correctly identified that women's fertility declined around the age of 35 years. Cooke and Nelson (2011) encapsulate the problem of measuring awareness, as because the main determinants of ART success are age and oocyte quality, ART cannot adequately compensate for women delaying childbearing. The transition period of perimenopause clearly signals the decline in reproductive capability, and some the general community may not be aware of this decline.

### **3.4 Timing Of Childbearing**

The mean age of Australian women having their first child has increased from 27.3 years in 1985 to 28.3 years in 1994 to 29.8 years in 2006 and 30.1 years in 2012 (Australian Bureau of Statistics, 2005; Hilder, Zhichao, Parker, Jahan, & Chambers, 2014; Laws & Hilder, 2008). Proportion of all women giving birth shows the number women aged 20–24 years having children has fallen from 17.1% to 14.6% from 1997 to 2006. Whereas rates for women 35 years or older have increased from 12.7% in 1994 to 18.8% in 2003 and to 21.4% in 2006 (Laws & Hilder, 2008).

Many women who try to start their family later in life will remain childless or have fewer children than they aspire (Barnes, 2001; Weston et al., 2004). More women are delaying childbearing to an age when they cannot conceive without fertility treatment and, thus, have an increased chance of involuntary childlessness (Leridon, 2008). As suggested:

“women make their own reproductive choices, but they do not make them just as they please; they do not make them under conditions which they themselves create but under social

conditions and constraints which they, as mere individuals, are powerless to change” (Petchesky, 1980: 675).

Women aged in their 30s and older often refer to their biological clock ticking which describes the process in woman’s reproductive life when fertility and conception may be difficult. Some women view their biological clock as an indicator for considerations on the timing of their childbearing (Friese, Becker, & Nachtigall, 2006; McKaughan, 1987).

Women compare their decision to start a family relative to their peers, so the timing of childbearing may be based on the opinions of others. Women may normalise the timing of childbearing when reproduction is risky or difficult (Daly & Bewley, 2013).

The age that women actually have children and the age considered an ideal age to conceive may differ. Weston et al. (2004) surveyed mothers and childless women aged 20 to 39 years of age about the ideal age to have children and found that mothers nominated that age as 26 years compared with childless women, who nominated an age of 28.1 years as the ideal age to have a child. Some women, due to their age, are having fewer children than their younger peers (MacDougall, Beyene, & Nachtigall, 2012) or fewer children than they imagined (Weston et al., 2004). A small cohort of men and women aged over 40 stated that later parenting was advantageous as financial security, careers, and relationships were established. On the other hand, conception was problematic; they would have fewer children, less energy, and fewer years to spend with offspring (MacDougall et al., 2012).

Bolvin et al. (2009) suggests that parenting outcomes from midlife intending mothers is not associated with poorer outcomes for children in the psychosocial context. Older mothers are thought to have better parenting practices than younger women due to their maturity, life experiences, financial and social resources, experience, resilience and understanding (Bolvin et al., 2009; Bornstein, Putnick, Joan, Suwalsky, & Motti Gini, 2006; Ferguson & Woodward, 1999; McMahan et al., 2011). Older mothers also tend to have richer and more responsive communication with their infants and toddlers based on their greater life experience in communication (Rowe, Pan, & Ayoib, 2005).

### **3.5 The Dilemma Of Motherhood Or Childlessness**

“Let’s face it, motherhood is a risk. You have no way of knowing if you’re going to like it until it’s too late. It’s the egg of life that can’t be unscrambled.” (Tuohy, 2011)

Reproduction is a natural part of a woman's life journey (Rowland, 1992). Views of motherhood are socially shaped by cultural meanings (McMahon, 2004) which define motherhood as central to the ways in which women are defined by others and to their perceptions of others (Phoenix & Woollett, 1991). Richardson (1993) suggests that women may feel a sense of importance and maturity when becoming a mother and women are strongly socialised to believe that marriage and motherhood are central to their lives and identity.

The decision to become a mother is shaped by nature, social structure (McMahon, 2004) sociocultural context, and women's personal views of motherhood (Ulrich & Weatherall, 2000). Rewards of childbearing may encompass personal achievement, emotional fulfilment, sense of identity, family continuity, happiness, and life enhancement (Sarantakos, 1996). Motherhood has been reported to offer relationship stability and provide a sense of purpose by, fulfilment, and may offer physical, psychological, and social completeness (Phoenix & Wollett, 1983; Ulrich & Weatherall, 2000). The decision to become a mother is not always socially and emotionally centred on women's lives (Badinter, 1981); however, motherhood is an achieved identity that, for some women, gives them strength and joy (McMahon, 2004). Infertility may be viewed as impairment, more so in low-income couples, as motherhood is an important role in Western societies (Phoenix & Wollett, 1983) and infertility as failure (Ulrich & Weatherall, 2000).

Unfortunately, motherhood is not possible for every woman. Although ART can assist with male and female barriers to conception, oocyte age-related changes cannot be reversed.

Before the development of ART, the only chance infertile couples had for a child for were adoption or childlessness. Adoptions are limited with few Australian children available to adopt, and couples source international adoptions. In 1971–72 there were almost 10,000 adoptions in Australia, but this number had dropped to 317 in 2013-2014, and most were inter-country adoptions (Australian Institute of Health and Welfare, 2014a). Adoptions are complicated and by the time the adoption application is initiated applicants may be too old to qualify to become an adoptive parent.

Not all women wish to be mothers (May, 1995), and developed societies are more accepting of a woman's choice to be childless (Dyer, 2014). In 2006 in Australia, seven percent of women aged 35–44 years were childless and had never been in a live-in relationship; they accounted for 29% of all childless women of this age. The lifetime rate of childlessness for Australian women is 25% (Australian Bureau of Statistics, 2009a, 2009b).

Considerations such as; advanced age, lack of a partner, and health problems are suggested as being pivotal factors in this circumstance (Rowland, 1992). Personal reasons such as a dislike of children, financial or career reasons, lifestyle choices, or concerns about bringing children into the world are all reasons for voluntary childlessness (Weston et al., 2004).

Haussenger (2005) challenges the perception that childlessness is socially acceptable; the fascination with childlessness is at fever pitch and underlies the uneasiness of women who are childless. Female identity is associated with motherhood, and childlessness is seen as a challenge to the societal norms because childless women are often stereotypically depicted as being personally unfulfilled (Morell, 2000). Involuntary childlessness is depicted as a failure to attain cultural norms, and this is seen to increase the medicalisation of childlessness (Nachtigall, Becker, & Wozny, 1992). Crowe (1987) as cited in (Ulrich & Weatherall, 2000) considers that many childless women have little choice but to seek medical intervention to avoid the stigmatisation associated with infertility.

Some women are childless by circumstance and not by choice (Cannold, 2000, 2005). Women who are circumstantially childless fall into two groups; women who are committed to motherhood and wait for a suitable partner or use donor sperm, or the women who are thwarted from motherhood by fertility problems, relationship, or career barriers (2000, 2005). Hewlett (2002) interviewed prominent women whose life circumstances had rendered them childless and she found that children were crowded out of their lives by high-maintenance careers and needy partners. A life without children may be by choice, chance, or by circumstance.

### **3.6 Social Factors Influencing Women's Childbearing Decisions – Childless By Circumstance Not By Choice**

“...people do not have enough control over their lives to plan exactly when they will have children” Das (2004: 4-5).

Australian women may be delaying their childbearing past the age when their mothers and grandmothers had children for a number of reasons, and it is suggested that social reasons have triggered this delay (Qu et al., 2000). Some women, despite having intentions to have children, can be childless not by choice, as external factors have overridden earlier intentions (Cannold, 2000). The timing surrounding a woman's first birth can be influenced by young adults who are postponing marriage and childbearing (Fussell,



2002). The availability of contraception along with expanded educational and occupational opportunities have empowered women to make choices about their lifestyle and childbearing decisions (Australian Bureau of Statistics, 2008a). Various factors such as socioeconomic status, education and employment, relationships, marital stability, health concerns and religion can influence pregnancy planning and the timing of childbearing (Baker, 2008; Holton, Rowe, & Fisher, 2011b; Weston et al., 2004; Wilkie, 1981). Cooke's (2010) meta-synthesis suggests a primary concern is the need for a supportive relationship partner. Petersen et al. (2015) found in their study of cohabiting and single women in Denmark, that having a relationship partner was not their prime concern but that the access to childcare and being able to combine work and children was of greater importance before childbearing.

The fertility rate in Australia as in developed countries is decreasing to below replacement rate (Baker, 2008). Advances in contraception, postponement of parenthood, and the development and promotion of ART are factors in delaying childbearing (Schritchfield, 2009). Alterations in social structure and traditional values such as the formation and constitution of families, premarital and unmarried cohabitation and later age of marriage are shaping women's intentions to have children and the number of children they aspire to have (Australian Bureau of Statistics, 1994b; Barber, 2000, 2001; Damario et al., 1999; Rindfuss & St.John, 1983; Weston et al., 2004). High costs of raising children, new economic roles for women, and improvements in gender equality are leading women to take on roles other than motherhood (Goldin, 2006; McDonald, 2000a, 2000b, 2001; Weston & Qu, 2001).

### **3.7 Relationship Between Education Level And Women's Childbearing Intentions.**

Research as early as 1969 indicated that women's decisions about childbearing were influenced by educational and religious factors (Stolka & Barnett, 1969) and that women's level of education changed the age at which they begin childbearing (Maxwell, 2007). Parity is lower for women who have higher levels of education (Barber, 2001; Rindfuss & St.John, 1983) and those professionals (such as doctors and lawyers) have the highest rates of childlessness of working women (Miranti, McNamara, Tanton, & Yap, 2009). In 1970, three percent of working age Australians has higher education qualifications that increased to 25% in 2011, and of these 57% were females (Australian Bureau of Statistics, 2012a). Women with non-school qualifications are more likely have a partnering relationship than women with higher education (Australian Bureau of Statistics, 2009b;

Birrell, 2004). Women with higher education and higher socioeconomic status are more likely to delay their childbearing and partnering, and have fewer children than women with lower socioeconomic status and less education, despite both groups having similar desires to have children (Australian Institute of Health and Welfare, 2011; Baker, 2008; Freeman-Wang & Beski, 2002; McDonald, 2002; Weston et al., 2004). Zoll (2013) suggests some educated women fantasise that they can rely on science to overcome infertility and believe that women can have it all.

### **3.8 Relationships Between Employment And Finances And Women's Childbearing Intentions**

Societal changes such as work and family compatibility and the desire of women to return to the workplace, and the aspiration for personal economic security such as housing stability are social factors that influence childbearing decisions (Newman, 2004; Wilkie, 1981) regardless of a women's socioeconomic status (Steele, Giles, Davies, & Moore, 2014). Some women postpone childbearing wishing to be financially secured before the financial demands of childrearing (Kravdal, 1994). Historically, benefits of having larger families waned when education policies legislated for compulsory childhood education rather than children contributing to household income (Baker, 2008). Women's increasing workforce participation from the 1980s to the present day has been a factor in Australia's low birth rate (Australian Bureau of Statistics, 2003a, 2012a). Women in the workforce contribute to later and less childbearing (Fussell, 2002; Gilding, 1997; Lesthaeghe, 1998; McDonald, 2000c, 2002). Women's level of attachment to employment may influence their decisions on timing of childbearing (McDonald, 2001; McGann & Conrad, 2007).

Some women may have difficulty balancing motherhood, paid employment, and marriage. Employers should provide maternity benefits during late pregnancy and after childbirth, and provide access to subsidised childcare to assist women returning to the workplace (Baker, 2008), with childcare essential for working mothers (Mahon, Bergqvist, & Brennan, 2016). Interrupting a career may be a difficult decision for some women as they may be concerned about their ability to re-enter the workforce and lost earning capacity.

Maher, Dever, Curtin and Singleton (2004) interviewed 114 Victorian men and women about how reproductive choices related to career, personal, and relationship plans. Maher concluded that the decision to become a parent is often complicated, and the provision of paid parental leave, affordable and accessible childcare, and flexible working practices are important considerations. Some women place their job or their career on hold until they

achieve a pregnancy because a prolonged period of accessing ART treatment can interfere with paid employment (Baker, 2003). Women, unlike men, may have to choose between parenthood and employment, and if they want work, must fit within responsibilities of parenthood (Richardson, 1993). In contrast, Petersen et al. (2015) found in a study of cohabitating and single childless women aged 35–43 years, that career was not a significant factor in delaying childbearing.

Women who predominately have casual employment are more likely to become a mother irrespective of socioeconomic status, relationship status, partner's educational level, or parental birthplace (Steele et al., 2014). However, characterising childless women as choosing career over family fails to acknowledge that there may be other reasons for childlessness and serves to group these women as selfish and ambitious. Women may not plan to postpone childbearing, and the inference to depict some women who delay childbearing as reluctant to leave a high paying professional occupation, is challenged by many women (Graham & Rich, 2014). Coleman (1988) agrees that midlife intending mothers provide greater financial and social capital, relevant to parenting and family development compared to younger mothers. Thus, some mothers are better able to support children financially as they have established careers, a home, and saved capital before the arrival of children (Wilkie, 1981). It would appear that policymakers should consider strategies to support mothers who wish to remain in the workforce (Lee & Gramotnev, 2006).

### **3.9 The Effects Of Personal Relationships On Women's Childbearing Intentions**

Changing marriage rates and marriage longevity are key features of the changing nature of Australian families and are reflected in fertility and childbearing patterns. Having children is considered an extension of a couple's relationship and a normal part of life (Sarantakos, 1996). For women in past generations, the purpose of marriage was for childbearing; however, current trends suggest that marriage and children are increasingly becoming a matter of personal choice. Women's average age at marriage increased from 21 in 1975 to 28 years of age in 2006 (Australian Bureau of Statistics, 1993, 2006a). The likelihood of marriage has decreased in recent decades and many young adults cohabitating will marry before or after children have entered the relationship (Australian Bureau of Statistics, 2007, 2009b; Birrell, 2004; Green, 2008). In 1971, 99% of cohabitating couples were married, which decreased by the year 2011 to 84% of cohabitating couples (Weston & Qu, 2013).

Relationship stability is declining with 33% of all marriages between 2000–2002 projected to end (Australian Bureau of Statistics, 2007). There appears to be an environment of relationship instability because of rising divorce rates; the divorce rate in 1995 was 12.0 and in 2000, was 12.9 per 1000 marriages. Loss of permanent legal relationships and time taken to establish new relationships lessens a woman's fertility options. Many women who divorce and remarry tend to be in the perimenopausal age group (mean age 38.6 years) and hence, at an age of diminishing fertility (Australian Bureau of Statistics, 2003a). Some Australians have multiple partnered relationships, and individuals aged 35–44 years can have multiple partnered relationships lasting a median of 6 years (Australian Bureau of Statistics, 2009b). As a consequence of relationship breakdown or instability, fewer children could be conceived. An absence of permanent relationships may lessen a woman's opportunity to have children or as many children as they aspire to have due to maternal age (Weston et al., 2004). A Danish study of 340 women aged 35–43 years attending the Fertility Assessment and Counselling Clinic in Copenhagen determined that higher levels of cohabitation a stable relationship with a partner to share the responsibility of children were prerequisites to childbearing (Petersen et al., 2015).

Before World War II, 15–24% of men did not marry and 10–17% of women aged in their 40s did not marry. This trend has continued to increase after a recovery in the marriage rates in the 1970s (Hugo, 2002). 1991, the marriage rates were; 20.4% for women and 27.6% for men aged 30–34 years, 11.1% for women and 14.9% for men aged 35–39 years, and 14.8% for women and 20.3% for men aged older than 40 years. Twenty years later, marriage rates had increased to; 31% for women and 35.8% for men aged 30–34 years, 14.8% for women and 19.3% for men aged 35–39 years, and 17% for women and 23% for men aged older than 40 years (Australian Bureau of Statistics, 2011).

Young adults are leaving home at an older age and forming partnering relationships later in life than in previous generations. Later relationships delay the age women may commit to a family (Australian Bureau of Statistics, 2003b; Fussell, 2002). Between 1979 and 2000, the percentage of young adults aged 20–29 years living in the family home increased from 46% to 52%, with 57% of young women aged in their 20s residing in the parental home (Weston & Parker, 2002; Weston et al., 2004; Weston et al., 2001).

### **3.10 Awareness Of Age Related Infertility**

Myths and misconceptions can be perpetuated among women such as believing that childbearing later in life is possible and which can shape childbearing decisions.

Wyndham, Figueira and Patrizio (2012) suggest that the misconceptions women hold about their fertility is alarming. Hashiloni-Dolev et al.(2011) surveyed 400 young female students on their knowledge of age-related infertility. Students were aware that fertility declines with age and had expectations that a conception was likely even into women's fourth decade. The authors suggest these myths are perpetuated by media coverage of older mothers and technological hype. Similarly, a Canadian study of 360 women aged 18–42 years were surveyed using the Reproductive Health Survey. Findings showed that although most were aware of fertility decline, around half overestimated the chance of a conception. They were supportive of the belief that natural conception was possible. Despite knowledge of age-related fertility decline, this was not seen as a factor in their childbearing intentions. An earlier study established that some women lack knowledge of age-related infertility regardless of age or level of education (Bretherick, Fairbrother, Avila, Harbord, & Robinson, 2010; 2012). Daniluk ,Koert and Cheung (2012) studied 3,345 childless women aged 20–50 years found a significant lack of knowledge by women of the consequences of age-related infertility, the availability and cost of ART, health risks associated with ART, and the age range of fertility decline. Kimberley-Smith's (2003) female undergraduate participants believed that women aged under 35 years should not be concerned about fertility decline because advanced ART would assist them. MacDougall et al.(2013) participants aged 40 years and older also were alarmed to learn that their perceptions of age-related fertility decline were inaccurate despite the fact that many women were well educated.

### **3.11 Knowledge And Health Behaviour Change**

Behaviour change can only occur with knowledge. In the case of infertility, knowledge of age-related infertility could be disseminated from primary health providers. Yu et al. (2016) studied obstetric and gynaecology residents and most agreed that such a speciality should initiate a discussion of age-related infertility with their patients. One-half overestimated the age of significant fertility decline and three-quarters overestimated the likelihood of ART success. However simplistic, with the assumption that ART can assist women who plan to delay childbearing by cryopreserving oocytes or embryos, or women who need ART for conception, the social pressures on women should be addressed as a health issue (Lemoine & Ravitsky, 2013). These studies suggest the need for an improvement in public education about the limits of women's fertility and the limitations of ART for age-related infertility, as the awareness of an issue may not result in a change in behaviour. However, little research has been undertaken on the most efficient types of

public education programs for this problem. Knowledge of age-related fertility decline does not necessarily change women's intentions as shown in a Canadian study of female undergraduates (Australian Bureau of Statistics, 2012a; Bretherick et al., 2010).

### **3.12 Summary**

In Australia, in the past two decades, changes in partnering relationships, family composition, and women's workplace participation have changed women's childbearing. Some women wish to have children at a later age for personal reasons at a particular stage of their life. Changes in the rates of childlessness can be related to societal changes such the rates of marriages and partnering.

Women who have postponed childbearing because of personal relationships are increasingly using ART as their only option. Consequently, for women, it seems that greater freedom of employment, reproductive choice, and changes in social boundaries are responsible for changes in the birth rate as women have greater control over these aspects of their lives.

Chapter 4 will explore the relationship between women and ART in Australia.

## **Chapter 4: Midlife motherhood and ART**

This chapter explores women's access to ART services in Australia. The number of midlife intending mothers attending infertility clinics is increasing, and there are many older women having ART. However, many women may not be aware of the health risks to the mother and/or child from this technology. Some risks are age related, and some are related to the technology, or the superovulatory drugs. ART cannot reverse the age-related decline in fertility and most midlife intending mothers using ART will not be successful. Medicare part-funds unlimited ART cycles for women of any age, which has assisted the expansion of infertility clinics.

### **4.1 Number And Ages Of Women Accessing ART In Australia**

The number of women aged 35–44 years giving birth has doubled, younger women aged 15–24 years are having fewer births, and birth rates for women aged 25–29 years are stable. Women entering an age of fertility decline are the fastest growing cohorts of mothers in Australia. Since ART started in Australia in 1978, the median age of women having their first child had increased by 3 years (Australian Bureau of Statistics, 2003a; Macaldowie et al., 2014). The average age at delivery of Australian women using ART is 35.1 years, which is 5 years older than for women in the community in 2010 (Li, Zeki, Hilder, & Sullivan, 2010).

The Fertility Society of Australia initiates an annual report from the Australian Institute of Health and Welfare (AIHW) compiled by the NPESU on ART cycles initiated in Australia and New Zealand. All infertility clinics, 80 in Australian and New Zealand in 2012, must supply cycle and outcome data to retain their clinic's accreditation to practice (Macaldowie et al., 2014). AIHW data show an annual increase in the number of clinics, cycles and maternal age of women attending infertility clinics. The AIHW data show there were 28,797 ART cycles in Australia and New Zealand in 2001 increasing to 67,980 autologous cycles in 2013 (Australian Institute of Health and Welfare, 2003; Macaldowie et al., 2015).

The average age of women undertaking ART cycles using their own oocytes in 2013 was 35.9 years, a slight increase from 35.5 years six years previously (Macaldowie et al., 2015; Wang, Healy, Black, & Sullivan, 2008b). Of all the ART cycles undertaken in 2012, women aged 35 and older undertook 64.1% of cycles, which represents an increase from 61% in

2008 (Macaldowie et al., 2014; Wang et al., 2010). One in four women aged 40 or older initiated autologous ART cycles, and the average age of women using donated oocytes or embryos was 40.7 years of age (Macaldowie et al., 2015).

An increase in the Australian midlife intending mothers using ART correlates with increases reported from other Western countries such as the United Kingdom. The Human Fertilisation and Embryology Authority (HFEA) showed a 10-fold increase in the number of women aged 40 and older accessing ART clinics (Hamm, 2007). Women aged over 35 years are twice as likely as younger women to present at infertility clinics with unexplained infertility (Maheshwari, Hamilton, & Bhattacharya, 2008; teVelde & Pearson, 2002).

## **4.2 Success Rates For ART**

Fecundability (the ability to reproduce) is dependent on many factors, including the ages of the man and the women, their health, and timing of intercourse. Leridon (2004) suggests the natural conception rate per month of around 23% for women aged 20–30 years of age. The live birth rate is also dependent on the foetal loss rate per month which ranged from approximately 12% of conceptions for women aged 20 years to 35% for women aged 45 years of age (Habbema et al., 2015). Success rates can be reported either as a conception or a live birth. ANZARD data and infertility clinic marketing may express ART success rates in a number of different ways that may include success per cycle, per oocyte retrieval, per embryo transfer, or cumulative success rate. Pregnancy rates will be higher than live birth rates as not all conceptions will proceed to term due to foetal loss. ANZARD data suggest that 21% of clinical ART pregnancies miscarried in 2013 (Macaldowie et al., 2015). ANZARD define a pregnancy as either; ongoing at 20 weeks gestation, ultrasound detection of an intrauterine sac with or without a foetal sac, chorionic villi present in products of conception, or laparoscopic or ultrasound detection of an ectopic pregnancy (Macaldowie et al., 2015). There is around a 20% chance of a conception each month and, after trying for 12 months, up to 90% of healthy couples will conceive (Leridon, 2004). In a study of 3011 women between 1998–2007 it was concluded that that ART can reach natural fertility rates but not exceed them (Gnoth et al., 2011). Women in midlife have fewer euploid embryos to transfer in an ART cycle compared with younger women because of age-related chromosomal changes (Harton et al., 2013). The chance of midlife mothers conceiving is half that of women 10 years younger (van Noord-Zaadstra et al., 1991).



In 1989, the AIHW reported 4,799 live births from 22 clinics in Australia and from three clinics in New Zealand (Rutnam, 1991). Ten years later, this had increased to 13,114 live births from 70 clinics in Australia and seven clinics in New Zealand, a 780% increase since 1987 (Wang, Macaldowie, Hayward, Chambers, & Sullivan, 2011b). Two per cent of babies born in Australia and New Zealand in 1998–1999 were ART conceived (Hurst & Lancaster, 2001); this increased to 3.1% in 2007, and 4.1% in 2012 (Li et al., 2015).

In 2013, in Australia and New Zealand, 37,192 women undertook 71,516 treatment cycles, with 23.8% resulting in pregnancies and 18.2% proceeding to a live birth for women of all ages. Most women were nulliparous and averaged 1.8 cycles per woman (Macaldowie et al., 2015). Live birth rates have not markedly improved since 2001 when multiple embryos transfer was commonplace and the viable pregnancy rate was 20.6 %, (Australian Institute of Health and Welfare, 2003). In 2013, women on average undertook 1.8 fresh and or thaw cycles. 48.9% of Australian women had two or more autologous cycles and 9.5% had four or more cycles (Macaldowie et al., 2015).

Success rates can also vary between the stage of the embryo transfer either cleavage or blastocyst stage. Cleavage stage embryos (with 4–8 cells) provide more embryos at transfer or to preserve compared with fewer embryos at a later stage blastocyst embryo transfer (up to 100 cells), as the embryos may not survive to the blastocyst stage. Blastocyst embryos have a higher implantation rate as they are more developed. Success rates for women from 2012 show that, for women of all ages, the birth rate for blastocyst stage embryos was 11.1% higher than that for cleavage stage embryos, and in 2013 the live delivery rate for women for all ages after blastocyst transfer was 28.4% (Macaldowie et al., 2015; Macaldowie et al., 2014).

Younger women have a higher success than older women. In 2013, the live birth rate per initiated cycle for women aged 35–39 years was 16.3%, per embryo cycle 23.1%, and per clinical pregnancy 74.8%. This compares with live birth rate per initiated cycle for women aged 40–44 years being 5.9%, per embryo cycle 9.2%, and per clinical pregnancy 58.5% (Macaldowie et al., 2015). Published ART success rates vary between different ART providers; live births rates for autologous cycles range from 19.8% to 29.0% for women aged younger than 35 years and from 9.6 to 15.7% for women aged over 35 year (Wang, Macaldowie, Hayward, Chambers, & Sullivan, 2011a). One reason for variations in success rates may be due to varying ages of women or different stages of embryo transfer.

Cumulative success rates can be based either on pregnancy or live birth rates. These rates include the initial stimulated cycle and subsequent transfer of any frozen embryos resulting from that stimulated cycle, and is the statistic frequently cited by infertility clinics. Cumulative success can give a higher rating than single cycle rates. In Australia between 2009 and 2011, the overall cumulative pregnancy rate was 54.9% for age 35–39 years, 29.4% for aged 40–44 years, and 3.5% for women aged 45 and older. The cumulative live birth rates were 40.7% for women aged 35–39 years and 16.4% for women aged 40–44 years, and 1.7% for those aged 45 years or older (Macaldowie et al., 2013). Cumulative success rates may increase the expectation of success compared with the single cycle rates reported above. Daya (2005) suggests that cumulative success rates are not appropriate for ART, as the scale for measuring the time span for all treatment cycles and the variability between treatment types (i.e., fresh embryo transfer or frozen embryo) does not give a comparable measure. However, clinics prefer to publish Cumulative Pregnancy Rates (CPR) because they tend to overestimate of the efficacy of treatment. An infertility clinic marketed their CPR for women 35–39 years as 45.2% and women aged 40 and older as 19.3%, compared with the ANZARD cycle data for 2009 as 24.3% for age 35–39 years and 10.9% for age 40 and older (Wang et al., 2011b). The cumulative live birth rate for all age groups was calculated as 21.1% after the first cycle, 31.1% after two cycles, 36% after three cycles, 38.6% after four cycles, and 40% after five cycles. There is little chance of a pregnancy after the fifth round of ART regardless of a woman's age, and the sixth cycle only increases the chance by 0.7% (Macaldowie et al., 2013).

### **4.3 Health Issues For Conception And Birth For Midlife Intending Mothers**

Medical complications for both mother and baby are more frequent in midlife intending mothers. As discussed in this chapter, most women accessing ART are of an age that is an independent risk factor for certain adverse events in pregnancy (Jolly, Sebire, Harris, Robinson, & Regan, 2000). Younger women have less ante-partum and intra-partum complications than women aged over 35 years (Bewley, Foo, & Braude, 2011; Braat, Schutte, Bernadus, Mooij, & van Leewen, 2010). Increased risks of adverse health outcomes for children born to midlife intending mothers are established in the literature.

### **4.4 Risks For Any Midlife Mother**

Midlife mothers have an independent risk for certain adverse events during pregnancy such as non-insulin-dependent diabetes mellitus, gestational diabetes, hypertension or

medical morbidity. Some of these conditions increase in occurrence with age and are of concern during pregnancy (Berkowitz, Skovron, Lapinski, & Berkowitz, 1990; Bianco, 1996; O'Connor & Johnson, 2005; van Katwijk & Peeters, 1998; van Noord-Zaadstra et al., 1991). Older mothers enter pregnancy with a higher incidence of pre-existing medical conditions, such as non insulin-dependent diabetes mellitus and hypertension (Bianco, 1996). Gestational diabetes occurs more frequently in this group because pancreatic beta-cell function and insulin sensitivity decrease with increasing age. Women entering pregnancy with a predisposition to non insulin-dependent diabetes mellitus are more likely to have an inadequate insulin response and increased insulin resistance than younger women (Jolly et al., 2000). There is a fivefold increase in gestational diabetes rates for women aged between 25–40 years with chronic hypertension is detected in 1.5% of these women (van Katwijk & Peeters, 1998).

Midlife intending mothers have a higher chance of gestational complications such as ectopic pregnancy, prolonged labour, placenta praevia, low birth weight (LBW), birth asphyxia and foetal growth restriction, pre-term delivery and delivery by Lower Section Caesarean Section (LSCS) rather than spontaneous vaginal delivery (van Katwijk & Peeters, 1998). Labour is more complicated and more dysfunctional in older women, and clinicians are more likely to recommend a LSCS delivery to avoid possible complications. In Australia in 2011, one-third of deliveries were by LSCS, with 41% of women aged 35–39 years, and 49% of those aged 40 years and older having a LSCS (Li, Z, Hilder, & Sullivan, 2013).

Nulliparous (a woman who has never given birth to a viable or live infant) older women have an increased risk of a having a foetus with a chromosome abnormality, an ectopic pregnancy, miscarriage or a stillbirth than nulliparous younger women (Freeman-Wang & Beski, 2002; Prysak, Lorenz, & Kisley, 1995). Women who have their first child when aged 35 or older have a significantly greater risk of complications of pregnancy and delivery compared with women of the same age who had already had at least one birth (Berkowitz et al., 1990; Nabukera, Wingate, Kirby, Owen, & Swaminathan, 2008; Pandian, Bhattacharya, & Templeton, 2001). The average miscarriage rate for women of all ages without an underlying chromosomal problem is 16.1% for women aged 35–39 years and this rate increases to 42.9% for women aged 40–44 years (Jansen, 2003). Midlife intending mothers have a risk of miscarrying a pregnancy, greater risks during pregnancy, and greater risk of a baby with congenital problems compared to younger women. However, despite the clinical risks, children of older mothers are shown to be at a lower

risk for behavioural and academic difficulties compared to women in their teens and twenties, conferring a protective maternal influence (Tearne, 2015).

#### **4.5 Risks In Using ART**

The rate of maternal death from medical complications in women aged 35–39 years of age is twice as high and for those aged 40 years and older is five times that of younger women (London, 2004), and most women using ART are aged 35 years and older. The numbers of initiated cycles for idiopathic infertility in the UK tripled between 2000 and 2011, whereas the number of cycles initiated for fallopian tubal problems decreased by one-third. Mol and Bhattacharya (2014) propose that the extended use of ART increases the risk of harm to babies because babies conceived through ART have more health concerns than naturally conceived babies.

ART may expose women to health complications caused by hormonal hyperstimulation. Ovarian hyperstimulation syndrome (OHSS) results from an excessive response to superovulation drugs and manifests as high oestrogen levels, increased ovarian size and fluid imbalance. Severe cases involve pleural effusion and compromised cardiac, renal and liver functions. OHSS is potentially a fatal condition because of its thromboembolic phenomena (Akagbosu, 1999; Assisted Reproductive Technologies Review Committee, 2006; Braude & Rowell, 2003a; Templeton, Morris, & Parslow, 1996). Bewley, Foo and Braude (2011) support notification of deaths from OHSS as required in Australia.

Women with ART-conceived pregnancies had a higher rate of LSCS than natural conceptions: 50.7% of women aged 35–39 years and 66.2% in women aged 40–44 years with ART-conceptions compared to 41% of mothers aged 35–39 years and 49% of mothers aged 40 years or older (Australian Institute of Health and Welfare, 2014b; Laws & Hilder, 2010; Wang et al., 2009; Wang et al., 2011b).

Handyside, Montag, Magli, Repping, Harper and Schmitzler (2012) suggest that the risks of advanced maternal age indicate a role for ovarian stimulation in perturbing meiosis in ageing oocyte. The use of superovulatory drugs to stimulate the ovaries of older women increases the chance of a chromosomally abnormal embryo. Handyside et al. (2012) used array comparative genomic hybridisation, which looks for chromosomal abnormalities in all 22 pairs of chromosomes, and found multiple aneuploidies in ART conceived embryos. This shows that ART can damage the oocytes, lessen the chance of a normal embryo, and increase the chance of a chromosomally abnormal baby. Routine non-invasive prenatal

screening screens for only three trisomies and sex chromosome abnormalities, and abnormalities on other chromosomes could be missed by screening compared to diagnostic testing such as karyotyping. Handyside et al. (2012) found that for both spontaneous and ART conceived pregnancies, trisomies occur mainly in female meiosis and mostly in the first meiotic division. Analysis of ART conceived oocytes from women aged between 33–44 years found that pre-division caused a lack of cohesion is a major factor in loss which may be due to a higher level of ovarian stimulation on aging oocytes. On the other hand, Pendina et al.(2014) did not find a significant difference in women aged 35 years or older. The Handyside study was conducted using comparative genomic hybridisation (CGH) and the Pendina study using standard karyotyping and as improved molecular techniques such as CGH or next generation sequencing improve, the question of whether ART has an adverse effect on oocytes will be clarified. Older women, whether using ART or not, should be aware of a greater chance of chromosomally aneuploid embryos and consider prenatal diagnostic sampling and karyotyping during early pregnancy (Handyside et al., 2012). Furthermore, as Kamphius et al (2014) demonstrates reviewing single embryo transfer with blastocyst transfer found an additional 50-70% risk of preterm and congenital malformation suggesting caution should be exhibited about using ART in couples where the benefit is questionable or there is a chance of a spontaneous conception.

#### **4.6 Risks To Babies Born To Midlife Intending Mothers And Women Using ART**

ART treatment contributes to a greater number of multiple births from multiple embryos transferred each cycle, with multiple pregnancies usually delivering before term. Multiple births are more likely than ART-conceived singletons to require neonatal care and have a LBW (Shieve et al., 2002). Perinatal outcomes for ART for either a singleton or multiple birth is reflected in greater usage of neonatal services and paediatric services for the first five years of life, which is a funding concern for health services (Chambers et al., 2013b). Reduction in multiple birth rates is occurring in Australia because of recommendations by the Fertility Society of Australia (FSA), which encourages single-embryo rather than multiple-embryos transfer per cycle (Fertility Society of Australia, 2005; Wang et al., 2009).

The average gestational age for Australian ART-conceived pregnancies in 2013 was 37.9 weeks (Macaldowie et al., 2015), which is shorter than the population average of 38.7 weeks (Hilder et al., 2014). Australian data show that ART- conceived twins were born at 34.8 weeks and overall Australian twin births averaged 35 weeks gestation (Hilder et al.,

2014; Macaldowie et al., 2015). ART-conceived infants born between 22 and 26 weeks have a higher incidence of long-term moderate to severe functional disability than do those conceived spontaneously (Abdel-Latif, Bajuk, Ward, Oei, & Badawi, 2013).

Preterm delivery usually results in LBW babies (World Health Organization, 1992). Singleton births for midlife intending mothers from ART-conceived pregnancies have significantly higher risk of LBW and in 2007 13% of Australian ART-conceived singleton babies had a LBW compared with 6.4% of Australian spontaneous-conception babies (Laws & Hilder, 2008; Shieve et al., 2002; Wang et al., 2011b). These differences are attributed to higher pre-term delivery rates for ART-conceived babies, although Marino (2014) suggests that the mode of ART, such as fresh-embryo transfer, results in a 250g reduction in birth weight. LBW contributes to 65–75% of neonatal deaths, and LBW ART-conceived infants may have ongoing health problems, which are associated with higher rates of hospitalisation compared to their full-term peers, and a greater risk of neonatal death (Marino et al., 2014; Tough et al., 2002). Marino (2014) confirmed an increased risk of LBW and preterm birth in Australian ovulation-induced women.

There is ongoing research indicating that girls born with a LBW or small for gestational age (SGA) have an increased risk of infertility in adulthood due to female fertility factor. Women with female factor infertility were twice as likely to have been born with LBW or SGA. In a Swedish study of 1206 births, babies with a LBW were 2.4 times and with SGA were 2.7 times more frequent in women with female factor infertility than male or idiopathic diagnosis. As ART-conceived babies have a higher risk of LBW, those conceived by ART may go on to have difficulty in conceiving naturally themselves later in life (Vikstrom, Hammar, Josefsson, Bladh, & Sydsjo, 2014).

ART pregnancies have an increased rate of stillbirth as confirmed by an Australian and a Danish study. A South Australian study between 1986–2002 of singletons conceived by ART compared to a state birth register showed that ART conceived singletons were more likely to be stillborn, and surviving babies had low birth weights and a higher chance of neonatal death compared with singletons conceived spontaneously (Marino et al., 2014). Research in Denmark has shown that ART conceptions have four times the chance of being stillborn compared to non-ART conceptions, (Wisborg, Ingerslev, & Henriksen, 2010). The Australian rates of perinatal mortality for ART-conceived births in 2007 were 1.4% (Laws & Hilder, 2008; Wang et al., 2009), which remains higher than the 1.03% for all Australian births in 2006.

Determining the risk of long-term health complications for ART-conceived babies is difficult, as health data can be difficult to obtain and environmental factors have to be excluded. Wilson and colleagues (2011) review article was unable to reach a conclusion about the likelihood of health problems for ART-conceived babies. Large longitudinal studies would assist these determinations. Smaller studies have shown that midlife intending mothers have an increased chance of delivering a baby with congenital defects that are genetically derived, and clinically present, with neonatal health problems (Nabukera et al., 2008). Older women can have children with increased health risks including higher rates of autistic spectrum disorder, cerebral palsy, cancer and mental retardation compared to women who are fertile (Blackburn-Starza, 2006; Croen, Najjar, Fireman, & Grether, 2007). Whereas, Halliday et al. (2014) researching ART-conceived offspring did not find an increase in occurrences of cognitive disability, autism or autism spectrum disorder in Australian young adults aged 18-28 years. Epidemiological data show that, regardless of age or family history, the population risk for any woman of having a child with congenital health anomalies is 3%. Katari, Turan, Bibikova, Erinle, Chalian and Foster (2009) found a 4–6% occurrence of congenital anomalies and Viot (2010) found a rate of 4.24% for ART-conceived babies which is not markedly different from the general population. Some subtle genetic changes indicating possible precursors in adult life of hypertension, non-insulin-dependent diabetes mellitus and cancer possibly due to epigenetic changes at time of conception are found in ART-conceived babies (Katari et al., 2009). Horwitz (2000) suggests that these epigenetic changes have been implicated in the development of obesity and non-insulin-dependent diabetes mellitus, and changes in gene expression have long-term effects on patterns of gene expression, which may manifest as health issues in future generations. Pontesilliet al. (2014) suggests that ART is responsible for babies having higher glucose levels which impacts on adverse cardiovascular and metabolic conditions during childhood compared to non-ART-conceived babies. Some of these studies have small sample sizes and long-term assessment of ART-conceived children is required to determine if clinical differences exist from such conceptions.

Midlife intending mothers using ART are more likely to have chromosomally abnormal embryos. These genetic abnormalities are mainly congenital cardiac conditions, malformations of the urogenital tract, retinoblastoma and angioma. It has been suggested that these malformations arise from genetic errors that occur during the ART procedures (Viot et al., 2010). DNA methylation controls which genes are expressed in certain cell types, and errors in methylation disturb embryonic development and can manifest as

clinical syndromes (Chang et al., 2011; Moisse, 2010). Methylation of DNA occurs when there is an interaction between environmental factors, such as the interaction between fertility treatment and genetic expression, (Katari et al., 2009). It is proposed that either the gametes or the embryos from the parents have abnormal epigenetic markers or the process of ART has allowed the methylation to take place, which increases the risk of a child having severe health problems. These can include imprinting, when the expression of a gene is expressed either maternally or paternally non-equivalently.

Some congenital genetic abnormalities involve imprinting genes for Angelmann Syndrome (AS), which manifests as intellectual disability and developmental delay, and Beckwith-Wiedmann Syndrome (BWS), an overgrowth disorder with gigantism, macroglossia, and an elevated risk of kidney tumours (Halliday, Oke, Breheny, Algar, & Amor, 2004). In the case of AS, a maternally inherited microdeletion on chromosome 15q manifests as severe mental retardation and small stature (Gardner & Sutherland, 2004). AS occurs in 1 in 15,000 to 20,000 births, but the risk increases to 1 in 4000 in ART-conceived children (Moisse, 2010). A 10-fold increase in BWS was observed in Canada with 1 in 1,300 ART conceived births compared to 1 in 13,000 in the general population with BWS (Blackwell, 2011). Gosden (2003) reported BWS 3–4 times higher after ART in three overseas locations compared with naturally conceived babies. Researchers are looking for the mechanism underlying such relationships between ART, imprinting genes and the environment (Chang et al., 2011; Tierling et al., 2011). Batcheller, Cardozo, Maguire, de Cherney and Segars (2011) support epigenetic changes as ART-conceived children have an increased risk for cardiometabolic abnormalities and genomic wide changes in DNA methylation. Some researchers question these associations and further research is required to clarify any associations (Odom & Segars, 2011).

Katari et al. (2009) found that conception in vitro is associated with small but statistically significant differences in methylation at CpG (cytosine-phosphate –guanine sites) sites compared to conception in vivo. This occurs when DNA methylation at CpG sites changes the cytosine to 5-methylcytosine (MeCpG). Handyside (2011) suggests that ovarian stimulation in ART may disturb the process of embryonic development as the chromosomes are separating prematurely, in particular the smaller sized chromosomes from 11 to 22. Embryos with errors in meiosis II, result in premature segregation of chromatids and chromosomally abnormal embryos, and will either spontaneously miscarry or result in a chromosomally abnormal foetus. Maternal age is related to age-related



oocyte degeneration with potentially serious genetic implications for ART conceived babies (Lim & Tsakok, 1997).

The long-term effects of infertility treatment are being studied longitudinally, but there is speculation that female children born to women who have received ovarian hyperstimulation might themselves have trouble with conception (Shelley, Venn, & Lumley, 1999). The first ART-conceived baby in Queensland now has delivered her own healthy child (Keeping, 2010). A genetic theory of a correlation between maternal age at conception and the lifespan of offspring, although modified by epigenetic factors, proposes that the mtDNA (mitochondrial DNA) in oocytes from older intending mothers may be at increased risk of a reduced lifespan. The mechanism of inheritance of compromised mtDNA suggests that mitochondrial metabolism in offspring would start at a less than optimal level of efficiency (Wilding, 2015). Genetic effects on offspring due to maternal age would benefit from further investigation.

Risk is evident for women having children in midlife, in particular for women aged over 40 years, so accurate information on inherent risks allows prioritisation of risk versus benefits allows informed choice. However, identifying the lowest risk option is not always appealing, as the desire for a child can override concerns about medical risks (Smajdor, 2011).

#### **4.7 Psychological Stressors Associated With Infertility And ART**

ART can be invasive, painful, expensive and time consuming, and hence have a profound and intense impact on people's lives (Salvatore et al., 2001). It is well known that infertility treatment is for some women a time of anxiety and stress. Wang et al. (2015) found, of 400 patients using ART, one-third had borderline or abnormal levels of anxiety and one-fifth had borderline or abnormal levels of depression. Findings from a study of 427 patients in 29 Dutch fertility clinics highlighted the importance and association between the level of patient-centeredness, quality of life, and levels of anxiety and depression (Aarts et al., 2011). Patients in two studies in Dutch infertility clinics expressed the need for more patient centred care, emotional support, continuity of care and access to their medical records to improve patient-centeredness (van Empel et al., 2010a; van Empel et al., 2010b). Dancet et al.(2010) suggest that fertility staff comprehend that patients, in addition to medical care, want to be treated like human beings.

The stressors associated with infertility are physical, emotional and financial. Infertility in one partner can emotionally affect the other partner and their extended social network (Greil, Slauson-Blevins, & McQuillan, 2010). Infertile women exhibit greater levels of anxiety and depression than control populations of fertile women, however it is unclear if these levels are clinically significant (Conrad, 1992; Cook, Parsons, Mason, & Golombok, 1989; Downey et al., 1992). Grief associated with infertility is compared with that experienced to the loss of a child, although it is the potential for loss of a wanted child rather than a physical loss (Lemeke, Pattison, Marshall, & Cowley, 2004:573). Heitman (1999) suggests that the profound despair after unsuccessful treatment is as overwhelming after initial hopes for success. There is a profound sense of loss when deciding to cease treatment so some women continue treatment to avoid grief (Tymstra, 2007). Some women find the hope instilled in them from the clinics make the decision to stop treatment difficult (Cummings, 2005).

The concept of psychogenic infertility treatment, in which infertility is caused by unconscious psychological factors, was thought to exist, although medical technology now disputes the notion that infertility arises from conscious thought (Wischmann, 2005). Facchinetti and Fazzo (2005) suggest that, as fertility is the norm, infertility is perceived as a failure of the couple, their friends, and family and is dependent on cultural norms. As noted earlier, many fertility treatment cycles may be unsuccessful with more than half of women using ART not having a baby and cycle failure an inescapable stress as women may anticipate cycle failure.

People often suffer psychological distress when faced with a life crisis such as infertility, which affects their self-esteem, sense of control over their lives and their social stability (Fouad & Fahje, 1989; Greil et al., 2010). A life crisis is the occurrence of an unexpected event that may affect the individual in a negative way or the lack of an expected transition of a rite of life passage, such as parenthood (Gerrity, 2001; Menning, 1977). A Japanese study found infertility and ART treatment can be a life crisis and the fourth most dramatic life event in a woman's life after the death of a parent or the infidelity of a life partner (Matsubayash et al., 2004).

The psychological effects for women can be long-term and can manifest as depression, lower life satisfaction and lower self-esteem for many years (Australian Institute of Health and Welfare, 2011; Beaurepaire, Jones, Thiering, Saunders, & Tennant, 1994; Bryson, Sykes, & Traub, 2000; Dunkel-Schetter & Lobel, 1991). Verhaak et al. (2006) found in their

long-term study of psychological adjustment, that despite anxiety and depression commonly experienced during treatment, these reduced over time even for those who were unsuccessful. Psychological conditions, such as anxiety, may occur more frequently in midlife intending mothers, and higher levels of anxiety are found in pregnant women aged 40 or older (Bevilacqua, Barad, Youchah, & Witt, 2000). Bradow (2012) used the Post Traumatic Stress Disorder (PTSD) Checklist-Civilian to evaluate PTSD in women exhibiting either primary or secondary infertility. Findings combined with quantitative data found that women with primary and secondary infertility had a frequency of PTSD instances six times the population level. Infertility is a traumatic event for some women which can lead to experiencing PTSD symptoms.

Women understandably experience positive emotions after a successful ART cycle and increased negative emotions after unsuccessful cycles. This can escalate after unsuccessful cycles leading to subclinical emotional problems in some women (Verhaak et al., 2006). Greil, McQuilian, Lowry and Screffer (2011) undertook a telephone study of 4,787 women aged 25–45 years of age and found that the treatment was associated with fertility-specific stress in addition to the stress of the infertility alone. Infertile women who do not undertake ART had lower levels of distress than did treated women. Treatment causes distress over and above that associated with being infertile, and this is not dependant on the length of treatment time or if a live birth was achieved (Anderson, Sharp, Rattray, & Irvine, 2003; Greil et al., 2011).

Psychological stressors can be accentuated for some women if they experience “victim blaming”. Van Balen (2002) suggests that victim-blaming is a psychogenic concept that increases the distress for women having ART because it places the cause and blame for infertility in the mind of the infertile woman, despite failure of the technology and not the woman. Victim blaming is a socially constructed belief system which seeks to make victims of others who are outside the social norm to maintain the social norms (Ryan, 1972). Victims are blamed for their situation, such as older women seeking infertility treatment (Sandelowski, 1986). The community may shame women for delaying childbearing by victim blaming, as women are solely blamed for the choice they made and partially responsible for the harm they experience (Pennings, 2001). Women may ask themselves if they have done enough to have a child.

Psychological emotions can also influence women’s decisions to have ART treatment or to discontinue treatment and remain childless. ART cycles can induce stress because of the

hormonal fluctuations during superovulation, cancelled cycles due to poor ovarian follicle development, failure of oocytes to fertilise, embryo implantation failure, early pregnancy failure, OHSS, and stress about the affordability of the ART. Stimulation cycles are cancelled more frequently for midlife intending mothers (often due failure to respond) and delays can be stressful as the chance to have a baby declines with each lost month. Women can have a roller-coaster ride of hope, anticipation, fantasy, elation, anxiety, disappointment, despair, and grief if a cycle is cancelled or unsuccessful. Repeated failed cycles become difficult for women to cope with, and grief can develop into depressive symptoms (Alesi, 2005). Between 2009 and 2011 of the over 44,000 Australian women who used ART, 264 women had 10 or more initiated cycles ART (Macaldowie et al., 2013). Treatment is difficult for women who do not have a successful outcome. Couples having their first cycle reported that their marital relationship improved as the couples supported each other (Holter et al., 2006), however other research found some women had depression or anxiety six months after unsuccessful treatment (Verhaak, Smeenk, van Minnen, Kremer, & Kraaimaat, 2005). Some women with involuntary childlessness experience long-term grief and feelings of social isolation (Ferland & Caron, 2013; Kirkman, 2001b). Zoll's (2013) book describes women depending on science to help them become mothers and some had to come to terms with their belief that women can have it all.

#### **4.8 The Marketing Of Hope Despite Risks**

ART is depicted as a mainstream medical procedure that is helpful for infertility despite the emotional, physical and financial costs involved (Diepenbrock, 2000). Lisa Jardine, the former chair of the Human Fertilisation and Embryology Authority, states that the world of IVF is a market of hope where users should be fully informed of its potential to deliver grief as well as success (BBC News, 2013). Health and illness provide the media with stories of technological miracles, magic and mystique. Media plays a major role in demystifying medical issues and has a pivotal role in the shaping of public opinion on medical problem and health risks. It can manipulate public opinion, educate the public and supply news items for the medical consumer market (Williams & Calnan, 1996b) (Williams & Calnan, 1996b)

Dramatisation and oversimplification of health issues by the media, may leave the individual with a distorted version of the facts (Lupton, 2005). In the case of infertility and ART, media gives a perception of tension between a biological imperative for children and

women's socio-cultural aspirations (MacDougall et al., 2013). Hurley (2013) suggests that this may be, in part, due to journalistic enthusiasm where promising new developments in ART are portrayed as proven without undergoing clinical trials. In the Australian print media, childless women are constructed as requiring sympathy and as career women first, and motherhood is depicted as a valued role. Thus, childless women may be portrayed negatively (Graham & Rich, 2014). Media welcomes the notion of a women's childless state being rectified by ART as generates public interest.

Media is a source of information for many individuals and interest groups and about social issues involving new technologies and scientific discoveries. Media releases are designed and promoted by professional public relations agencies (Raymond, 1990; Valiverronen, 2004). An integral part of such media promotions through media is "creating the need" for of a new drug or technology (Moynihan & Henry, 2006). Media is one of the main sites where cultural images of biotechnology and genetics evolve and are circulated (Valiverronen, 2004). Through newspapers, magazines, television and other sources, media can influence ideas, decisions and perception and advance social change through successful marketing (Kotler & Zaltman, 1971).

ART offers more promise than performance as depicted in the language, images and themes of success as conveyed in the media, and highlights the miracles stories and the technical abilities of ART. The media is a popular source of information regarding ART, and there is widespread public acceptance of ART as a routine medical procedure (Cline & Haynes, 2001). ART as a fall-back option is normalised through the media portrayal of medical specialists and successful patients. Newspapers and women's magazines give women encouragement despite the fact that many older patients are not successful (BBC News, 2013). Shanahan (2012) highlights the marketing for some Canberra IVF clinics, which have advertised on daytime television using attractive young ART participants, when in reality most women who use ART aged in the middle 30s, in soap-opera type scenarios to promote the use of ART. Zoll (2013) discusses a culture of hope and success reinforced by the fertility clinics, in which women do not discuss failed cycles and the inability of ART to solve reproductive problems, and there is an absence of truth. Zoll argues that such a culture of hope and success is misleading.

Media influences community attitudes about reproductive choices, such as childbearing and contraception. A study that provided online educational information to a group of undergraduates on fertility, ART, and delaying childbearing resulted in an increase in

knowledge on fertility and a change in intention to have children at an earlier age (Wojcieszek & Thompson, 2013). Despite the benefits and availability of online resources, Daniluk (2015) found in a study of 199 men and women aged 18–35 years that fertility knowledge and ART initially improved after viewing online sources, but decreased to pre-intervention levels after six months, particularly for male participants. Online education may be beneficial however the extent of retention of that information over the longer term is unknown. Holton et al. (Holton et al., 2016) found Facebook an effective media tool for young women to discuss reproductive health issues.

Media has been accused of playing on the desire for easy technological solutions to problems of infertility (Nelkin, 1995). Media portrayal of success stories has been in the public domain since the early years of ART in Australia. Nobel and Bell (1992:25) analysed Australian press articles about ART for six months in 1988, and found numerous sources in the articles about women who had been successful, medical miracles, and little coverage of risks or psychological issues. Analysis of British print media in 2009 found little discussion of the risks of pregnancy and birth in older women and reinforced the notion that ART could solve fertility problems including ageing (Mills, Lavender, & Lavender, 2015). On the other hand, a Canadian study found that 63% of newspaper articles in the Canadian press from 2005 to 2011 discussed the risks of ART (King et al., 2014). The aforementioned Canadian study found almost half of the newspaper articles depicted a medical miracle with stories of women bearing children aged in their 60's and 70's depicted positively, but there was limited criticism of the technology. Technological advances in ART, as depicted in the media, helping to compensate for age-related fertility decline, may influence women to delay their childbearing (Leader, 2006). There is often scarce coverage of the many women who have not had successful cycles. The anecdotal personalisation of ART success stories contains minimal scientific empirical data and often omits the personal and financial costs, the risks of the technology, or the success rate versus the failure rate. ANZARD data indicate that, that for older women, inability to conceive rather than success is the most likely scenario contrary to the media stories of older mothers or celebrity mothers (Firth, 2005; Fitzmaurice & Wood, 2004; Gosse, 2006; Macaldowie et al., 2014; Wildman, 2006).

The normalisation of reproductive medicine also occurs through women's magazines. The discourse of women and their ART success in these magazines appears to follow a number of formulae (Diepenbrock, 2000). Having a baby is thus normalised, and infertility is portrayed as a devastating experience. One of these constructs is that normal women

want to have babies. Media has depicted medical technology as normalising ART treatment for the ordinary woman who endures pain and discomfort to gain her goal of a perfect child and who is assisted by a benevolent and humble medical specialist (Diepenbrock, 2000; Gibson, 2004; McLean, 2004). Consequently, women may have unrealistic perceptions of ART specialists, procedures, abilities and limitations (Bell, 2006; Peddie, van Teijlingen, & Bhattacharya, 2005).

As the knowledge gap between doctor and patient lessens, medical practitioners become challenged as holders of expert knowledge (Kirkman, 2001a). Medical information in the media is often written as a sales pitch promoting the expertise and the success rates of clinics and is portrayed as in the public interest rather than as an advertisement (Halpern, 1989). Such information provided by a professional, even if they have a vested interest, will create more interest and credibility than from a member of the public (Lupton, 2005), as illustrated in Canadian newspapers where almost half of the articles were cited by ART experts (King et al., 2014). A move to use social media to disseminate medical information on the limits of women's fertility, and the capabilities and limitations of ART, could provide healthcare information which is effective and efficient provided the source is authoritative and without industry direction (Lupton, 2005), and counteracts the unrealistic portrayal of ART in the media. The difficulty in determining the level of engagement with health-care information and the effectiveness of social media, as a health-promotion tool is yet to be determined (Noble & McDonagh, 2014). Primary health providers should guide their patients to online sites that provide expert information (Fahy, Hardiker, Fox, & Mackay, 2014; King et al., 2014).

Kimberley-Smith's (2003) research showed that female undergraduate students have an unrealistic sense of security of delayed motherhood and the success of ART and that the media portrayal of images of celebrity births to older parents contributes to this lack of awareness of age-related fertility. Media coverage of celebrities having miracle babies after the age of 40 years gives women the impression that there are no age barriers for conception and that ART can extend the age at which women can be fertile (Caplan & Patrizio, 2010).

Another false assumption of the success of ART is the portrayal of the technology by doctors and infertility clinics. As Haussenger (2005) suggests, women could have unfounded expectations of ART because marketing campaigns of infertility clinics tend to hide the discouraging facts of ART and to promote pregnancy at any cost. Media may

influence decisions on the timing of childbearing and success of ART, and individuals may have trouble understanding statistical information and medical technology so the communication of information in an easily understandable format is vital. However, some unwise decisions do not originate from misinformation or incorrectly interpreted information and should not always be attributed to these factors (Smajdor, 2011). Education and information implemented by government agencies could improve community knowledge (Lemoine & Ravitsky, 2013).

#### **4.9 Accreditation And Governance Of ART In Australia**

Most states have some form of regulation to govern the use of ART except Queensland, which had no legislation specifically relating to ART (Cohen et al., 2005; Dawson, 1994). Currently, three Australian states have legislation relating to ART; Assisted Reproductive Treatment Act (2008) in Victoria, the Assisted Reproductive Treatment Act (1988) South Australian, and the Human Reproductive Technology Act (1991) in Western Australian (Bell, 2006). The National Health and Medical Research Council (NHMRC) operates under the guidelines of the Commonwealth legislations the Prohibition of Human Cloning for Reproduction Act 2002 and the Research Involving Human Embryos Act 2002 (National Health and Medical Research Council, 2007). Clinics can practice ART without being accredited; however, any procedures using embryos have to be accredited by the Reproductive Technology Accreditation Committee (RTAC) under their guidelines. In 1986 the FSA introduced a Code of Practice for Assisted Reproductive Technology Units with the role of RTAC to develop program standards for ART clinics in Australia and New Zealand and to carry out the accreditation of ART units under FSA guidelines (Assisted Reproductive Technologies Review Committee, 2006). The guidelines for RTAC were consistent with the Ethical Guidelines on Assisted Reproductive Technology 1996 and 2004 produced by the NHMRC (Assisted Reproductive Technologies Review Committee, 2006). This Code of Practice was revised in 2008 and introduced compulsory actions and requirements to improve the standard of care, and to ensure minimum standards were met by ART clinics and to compel the clinics to function within a documented Quality Management System (Fertility Society of Australia, 2009).

The NPESU was supported by the FSA to establish a register of, and the outcome of, ART cycles. This register is the only credible source of information on ART cycles and success rates in Australian and New Zealand. The initial report collected data from 12 units in Australia and one in New Zealand, and now reports on all ART units in Australasia (Ford,



Nassar, Sullivan, Chambers, & Lancaster, 2003). The FSA initiated a self-regulated process with the RTAC, which was formulated with the support of the federal health minister (Saunders, 2005). Shanahan (2012) suggests that this industry self-regulation confers a special ethical status to itself and the industry moves the ethical goalposts when a new technique is proposed. Kamphius (2014) suggests that the ART industry may be overused, and the industry should evaluate offering early ART intervention, which may have risks, instead of pursuing a natural conception. Kersten (2015a) found evidence of overtreatment within the Dutch population with intervention occurred in 36% of couples, who were mainly older primagravidas who may have conceived naturally within 1 year of trying to conceive, or started ART treatment earlier than the six-month management plan, which was considered to be overtreatment. It was suggested that a treatment plan is initiated for patients who may be able to conceive with minimal intervention.

#### **4.10 The History Of Public Funding Of ART In Australia**

In Australia, health expenditure consumes around 9.1% of the gross domestic product (GDP), which is lower than other comparable OECD countries (9.6%) and significantly lower than the USA (17%) (Duckett, 2007, :37; OECD, 2011). In 2005, the Australian ART industry was valued at \$170 million; this is estimated to be growing at the rate of 8-10% annually in Australia as in other high-income countries (Chambers, Sullivan, Ishihara, Chapman, & Adamson, 2009). There is a growing need to make healthcare expenditure more sustainable, and as Medicare funds ART, expenditure should be under constant review (Chambers et al., 2012a). Australia provides public funding for an unlimited number of ART cycles for women who are eligible for Medicare funding. Many other developed countries place a limit on public funding for ART, so Australia bears a greater burden for this health funding compared to other countries (Assisted Reproductive Technologies Review Committee, 2006).

The Medical Benefits Scheme (MBS) and the Pharmaceutical Benefit Scheme (PBS) subsidise infertility treatments and hormonal drugs for ART treatment, and thus permit greater equity for all Australian citizens wishing to access ART. The Health Insurance Commission, as Medicare, provides funding for ART for certain Medicare item numbers (13200 to 13221), which pertain to assisted reproductive services (Australian Government Department of Health and Aging, 2009). ART services were included in the Medicare Schedule as an initiative of the Hawke Labor government in 1990; before that, all treatment costs were born by the consumer.

The MBS was costed at \$108.6 billion in the year 2004 and ART accounted for 0.25% of total health expenditure in Australia (Chambers et al., 2009). In 2006, the total cost of a standard ART cycle was estimated to be 14% of the per capita Gross National Income (GNI), which equated to 6% for an Australian individual after Medicare and the PBS subsidy (Chambers et al., 2009). MBS costing for a single ART cycle including the PBS, rose from \$5768 in 2006 to \$7488 in 2010 (Chambers et al., 2011). A report to the Australian Parliament in 2015 showed that ART services are funded under Section 100 of the *Schedule of the Pharmaceutical Benefits* and during reporting year 2013-2014, \$85.5M funded ART, which is 4.2% of the annual PBS expenditure. ART expenditure averages a 3.3% annual growth rate (Harvey & de Boer, 2015).

It is understandable that in the early days of ART, success rates were significantly lower than current success rates and Medicare covered a lifetime funding of six stimulated cycles per woman. Once the lifetime limit was reached, women had to fund the treatment costs themselves and could have an unlimited number of self-funded cycles (Kovacs et al., 2003; Smith, 2006). The figure of six funded cycles was initially proposed, as 90% of women would conceive within four or fewer stimulated cycles. However, this figure was challenged as only 50% of women were achieving conception after four to five cycles (Kovacs et al., 2003; Saunders & Satchwell, 1995).

A concerted public campaign by infertility clinicians, consumers and ART support groups such as Access Australia challenged the federal government to abolish the capped six-cycle limit. The campaign was successful and in 2000, this limit was abolished and unlimited government reimbursement was provided for ART with no limitations on the number of stimulated cycles (Nogrady, 2008). Australia is the only country in the world with unlimited publically funded ART cycles. Sweden and Britain have a three-cycle limit with an age limit of 39 years and New Zealand a two-cycle limit. Limited funding for ART in Britain has resulted in a greater scrutiny on spending on ART services. Shanahan (2012) suggests Australians have a unique sense of entitlement for unrestricted public funding for ART as demonstrated when proposals to limit Medicare funding for ART is strongly challenged by interest groups.

The next major change to Medicare rebates for ART was the introduction of the Medicare Safety Net (MSN) in March 2000, proposed by Tony Abbott, the Health Minister in the Howard Liberal government (van Gool, 2004). The EMSN was introduced in March 2004 and allowed the government to meet 80% of the out-of-pocket expenses (i.e., not covered

by Medicare) in a stimulated cycle once the threshold of \$700 was spent in a year by non-concession card holders (Assisted Reproductive Technologies Review Committee, 2007; Australian Government Department of Health and Aging, 2005; Smith, 2006). The scheme was originally designed to help the elderly, chronically sick and disabled to fund medical treatment (Dunlevy, 2007) by covering the out-of-pocket expenses by refunding 80% of medical costs above the threshold.

The Extended Medicare Safety Net (EMSN) was designed to allow higher costing medical claims to be better compensated and to improve equity for medical services. The EMSN was expanded in 2004 and increased the subsidies for claims above the threshold, such as \$300 for concession cardholders (Australian Government Department of Health and Aging, 2014). However, this was not achieved as clinicians increased their fees which permitted patients to reach the threshold earlier, so the patients out-of-pocket costs did not change and the clinicians revenue increased and Scott (2015) suggests that this was especially lucrative for infertility clinics. Van Gool (2009) describes that the EMSN, which aspired to improve equity in medical care, in reality created greater inequality as EMSN is related to income, so higher earning individuals users of ART and obstetric services were the greatest beneficiaries of the scheme.

The nominated out-of-pocket expenditure to qualify for the EMSN for ART recipients was reached after one ART cycle, enabling 80% of cycle costs refunded for the remainder of that calendar year (Chambers et al., 2012a). Those qualifying for the EMSN had their out-of-pocket expenses for a fresh IVF cycle reduced from \$4000 to \$1500. Due to reduced out-of-pocket expenses, attendance at ART clinics increased by 72% over 5 years from 31,200 cycles in 2003 to 53,600 in 2008, and Medicare benefits for ART increased 300% from \$50 M to \$202.2 M under the EMSN scheme (Chambers et al., 2012b).

One Queensland clinic encouraged women to engage in further ART cycles, which they may have not been able to afford previously, as Medicare would cover the majority of their out of pocket expense (Harris, 2007). Undeniably, the EMSN allowed some women to continue having ART cycles when it was evident that they had little chance of conception. Overall, the EMSN had not made Medicare services more accessible for Australians living in the lower socio-economic quintile (Chambers et al., 2013b). The cessation of the EMSN and the capping of the Medicare rebates for ART resulted in a 13% decrease in the number of treatment cycles in 2008 (Macaldowie et al., 2010). It appears that the EMSN

was a boom to the fiscal running of infertility clinics and was, at times, not in the best interests of women.

Infertility clinician Dr. Richard Henshaw claims that underperforming preforming clinics are costing Medicare, private health funds, and individuals more than the best clinics. There was a seven-fold difference in the success rates between the best and poorest performing clinics. The clinics in the top 25 percentile cost around \$2 million of Medicare funding to produce 100 babies, whereas the clinic in the lowest 25 percentile costs \$6 million dollars for 100 babies. Women would benefit from accessing ANZARD data to find clinics with the highest success rates, however the Fertility Society of Australia will not release such data to consumers (Swan, 2015). This stance is under review by the ACCC (Australian Competition and Consumer Commission, 2015).

#### **4.11 Summary**

The number of cycles of ART in Australia has increased at a rate of around 2% from 2012 to 2013. One in four autologous cycles were undertaken by women aged 40 years or older, and for this age group, age-related oocytes degeneration will be an impediment to conception and a live delivery (Macaldowie et al., 2015). On average, older women have fewer and poorer quality embryos available for transfer and a higher miscarriage rate compared to younger women. They have a higher probability of having a child with a chromosomal abnormality due to age-related chromosomal abnormalities than younger women.

Midlife intending mothers using ART can have a higher risk of health problems because of their age, a greater risk of having a low birth weight baby due to female factor infertility, and a greater chance of needing neonatal intervention than younger women. There are more adverse perinatal outcomes for ART-conceived babies than from babies born from spontaneous conception.

In addition to medical risks associated with ART, the frequency and the scope of psychological risks are increased for women using ART. Anxiety, depression, and lowered self-esteem are emotions associated with ART, regardless of whether the cycle is successful or not. The normalisation of ART through the media and medical marketing depicts ART as a successful medical procedure and consequently, the failure to conceive after ART compounds psychological distress.

Media stories of older mothers and the marketing of ART stories of achievements may be responsible for unrealistic belief in the success of ART. Stories about medical breakthroughs can give a false sense of security about delaying childbearing and using ART to rectify the problem (Glover, Gannon, Sherr, & Abel, 1996; Kimberley-Smith 2003; Maheshwari, Porter, Shetty, & Bhattacharya, 2007; O'Connor & Johnson, 2005). Media accounts can also report a biased view of ART behind glamorous stories, which may be misleading for infertile women (Condit, 1996).

Costs for ART services are continually rising as expectations of ART increase. Since the corporatisation of many Australian infertility clinics, there appears to be a push for advanced and expensive scientific technology and more invasive and costly ART treatments. Rising costs in the health sector are of concern to governments.

Research indicates that if a pregnancy does not occur within five stimulated cycles, the chance of success with further cycles is limited. Unrestricted Medicare rebates for ART, particularly for women aged 40 and older with a lowered success rate, warrants scrutiny of Medicare funding guidelines. Women who can afford the out-of-pocket treatment costs of ART have greater opportunities for conception than those less financially secure.

#### **4.12 Research Questions**

The review of the literature in Chapters 2 to 4 encompassing this research topic shapes the research questions. These are as follows:

The following eight questions were investigated in this research.

- 1 What are the views of women who have engaged with ART about their clinic experience?
- 2 What were women's expectations of the success of ART?
- 3 What are the views of women involved with ART on women's age-related fertility decline, childbearing decisions, the success of ART, and impact of media and marketing on childbearing decisions?
- 4 What are the beliefs of the community towards women's age-related fertility decline, childbearing decisions, success of ART, and impact of media and marketing on childbearing decisions?
- 5 Do social factors such as; career and work, educational attainment, financial security, health or partnering relationship influence women's childbearing intentions?
- 6 Is there a perception among the general population and consumers of ART

that infertility is medicalised and its treatment commodified?

- 7 What are the social and psychological impacts for women using ART?
- 8 Do women who have engaged with ART have recommendations for women in the community regarding the timing of childbearing and ART?

## **Chapter 5: Research Methodology**

### **5.1 Introduction**

This exploratory research aims to contribute to the existing knowledge of women's experiences of ART, expectations of the technology, factors influencing both the decisions to have children in midlife and to use ART. Chapter 5 outlines the sampling and methods of data collection used to explore these issues with women who have engaged in ART and a community group of men and women who may have little or no experience of ART.

The investigative procedure of the research is shown in Figure 5.1. A pilot study (Group A) was initiated in 2007 while the researcher was employed at one of the research sites, an infertility clinic in Queensland. The pilot study was informed by a review of the literature and informal discussions with midlife intending mothers attending an infertility clinic. Responses from the pilot study guided the research for the two surveys for Groups B and C and the interviews for Group D.

### **5.2 Methodology**

Initially it was anticipated that sufficient data for the research would be sourced from the surveys. However, after reviewing the findings, the researcher decided that the survey data could be enriched by interviews with women who had used ART. The qualitative findings were supported by the interviews and allowed the research questions to be discussed in greater depth (Cameron, 2009; Cresswell & Plano Clark, 2011; Cresswell, Plano Clark, Gutmann, & Hanson, 2003; Cresswell & Tashakkori, 2007).

A mixed-methods approach was adopted as the most appropriate design to address the research questions. The rationale for using this method was to better understand the research problem by converging both the statistical trends from quantitative data with the insightful details of qualitative research (Cresswell & Tashakkori, 2007; Greene, 2008; Johnson, Onwuegbuzie, & Turner, 2007). A sequential mixed-methods approach was deemed to be appropriate. This method uses one method of data collection (quantitative) and builds on those data with the second method of data collection (qualitative) (Cresswell & Plano Clark, 2011; Cresswell et al., 2003). This design allowed survey data to be collected and analysed and, informed and guided by these findings, qualitative research was undertaken through in-depth interviews.

A study based solely on quantitative methods risks overlooking critical features of human phenomena so that results are sometimes of limited value (depending on the area of research) (Hathaway, 1995). One weakness of quantitative research is that it may de-contextualise human behaviour in a way that removes it from the real-world setting and ignores the variables not included in the model being used. In this study, the quantitative research does not intensely question participants on their experience of ART but has the advantage of being able to analyse responses from a larger number of participants over a large geographical area and to identify any statistically significant results (Cresswell & Tashakkori, 2007).

A solely qualitative study risks the criticism of being too subjective and without rigour, as no reproducible empirical data can be obtained by this method (as per the scientific method paradigm) (Schultze, 2003). However, the rich, in-depth responses from a small number of interview participants gives greater insight into the research question and can enrich the data obtained from the quantitative study (Crotty, 1998). The combination of these two methods was deemed to be an effective way to explore the research questions. Central themes were established with the survey data and then studied more deeply via interviews.

Johnson, Onwuegbuzie and Turner (2007) suggest that mixed-methods research combines qualitative and quantitative research in viewpoints, data collection, analysis and inferences. Only by using both methods can the breadth, depth and richness of the research be fully realised (Palton, 1990; Schultze, 2003). Haynes (2012) discusses that the concept that reflexivity can allow the researcher to influence the research design and its interpretation, which was recognised by the investigator.

The researcher did not have any personal reasons such as personal engagement with ART, delaying childbearing or involuntary childlessness for undertaking the research. The researcher has worked within an infertility clinic for 17 years, but was not employed by an clinic for most of the duration of the study.

### **5.2.1 Study design**

The mixed methods approach is outlined in Figure 5.1. Purposive sampling was used in the pilot (Group A), support group survey (Groups B) and the interviews (Group D) to ensure that participants provided greater insight into the research questions (Devers & Frankel, 2000). Purposive sampling allowed the researcher to use their experience and



knowledge of the intricacies of the samples to devise the surveys and interviews (Ritchie, Lewis, Elam, Tennant, & Rahim, 2013). Participants were selected because they had unifying characteristics related to the research such as having experienced ART treatment, which allowed more in-depth analysis (Patton, 1990). For some responses, results were also analysed according to gender and age because these have been identified as significant factors in the literature (Bianco, 1996; Bornstein et al., 2006; Damario et al., 1999). These groups were aged; 35–39 years and 40 years of age, and categorised as such in ANZARD data (Macaldowie et al., 2015). Chapter 9 reports data separately from the open-ended questions in Group B and the interview data from Group D as recommended by Foddy (1993).

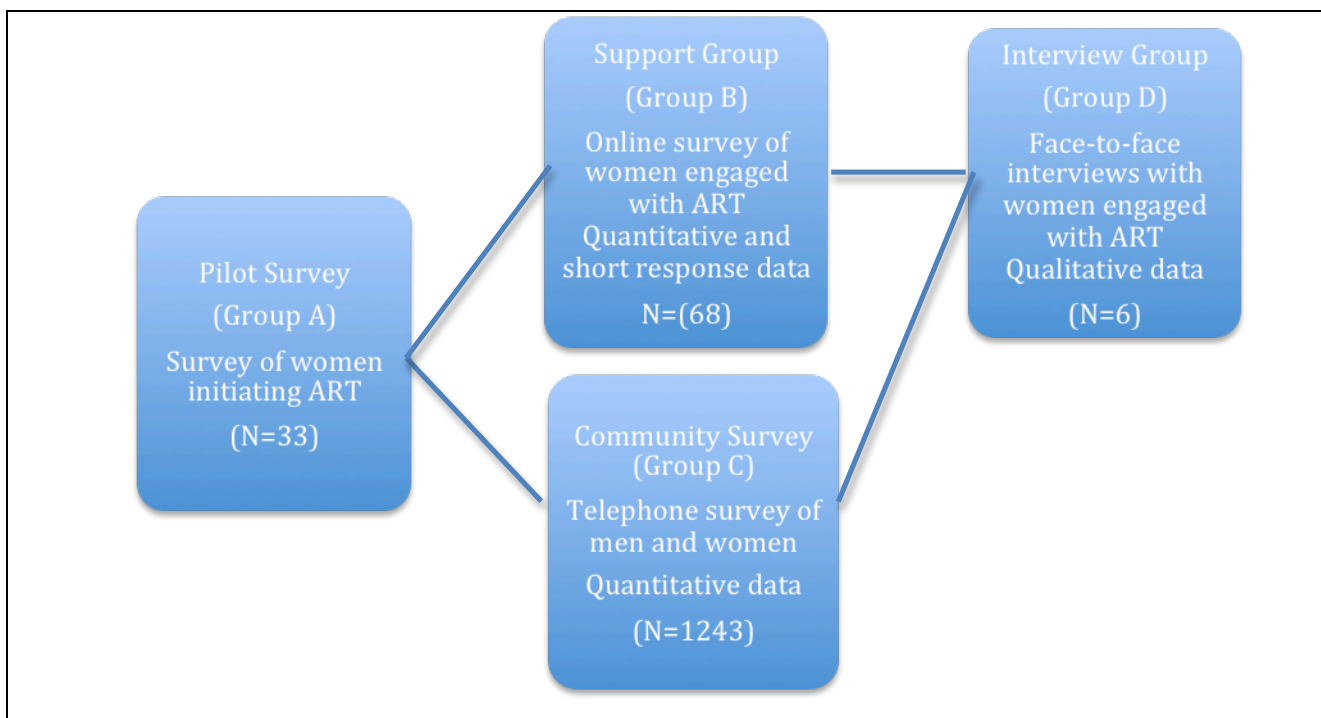
### **5.2.2 Study Groups:**

The study design comprised; Group A: a survey (pilot survey) of midlife intending mothers attending a Queensland infertility clinic who had not undertaken ART treatment but consulted a clinician and an infertility nurse (N=33). This study was used solely to refine the methodology and research questions.

Group B: a quantitative study comprising an online survey of women, aged 35 years and older, who were members of a Queensland infertility clinic's support group and had engaged in ART treatment. There was also a qualitative component with an option to leave comments (N=68);

Group C: a quantitative study comprising a telephone survey of a sample of male and female Queensland community members (N=1243);

Group D: a qualitative study involving face-to-face interviews with midlife intending mothers attending a different Queensland infertility clinic who had engaged with ART (N=6).



**Figure 5-1 Research Plan for Groups A, B ,C & D**

### **5.3 Group A: Pilot Study**

Women who were newly registered patients of a Queensland infertility clinic were invited to participate in the pilot study. Constraints of the recruitment process only permitted access to women aged 38 years or older. The purpose was to determine if participants would be willing to respond to such a survey due to sensitivity of the issues; this would inform the methods for a longer study. The pilot study was not intended to provide data for analysis.

These women had registered with the program but had not commenced any ART treatment. Women in the pilot survey (Group A) attended their clinic between May 2006 and July 2008 as registered patients and ranged in age from 38 to 45 years. They were invited to participate by a fertility nurse who gave participants a brief outline of the research, an information sheet, consent form, survey form and a stamped addressed envelope for return of their completed survey. Participants were informed that participation in this research would in no way influence their treatment at their clinic. 100 surveys were distributed, and 33 surveys were completed and returned to the researcher, representing a 33% response rate. Comments on question flow and survey design were noted and used to design the questionnaire for Group B. The researcher encountered problems with survey distribution that may have contributed to the response rate. An analysis determined that sample size was small and using participants aged from 38 years of age was not

entirely appropriate for this research, for instance, as age restrictions led to lower response rates and fewer participants. The pilot determined that women were uncomfortable discussing the aetiology of their infertility or were uncertain of the aetiology. For those reasons, and as access to infertility patient's clinical data was unavailable, it was proposed to survey women through the support group to improve the response rate and to survey women who accessed ART from the age of 35 years.

## **5.4 Group B: Support Group Study**

### **5.4.1 Participants.**

Women who had engaged with ART and were registered patients of a Queensland infertility clinic were invited to participate in an online survey by the coordinator of their support group. The committee of the support group approved the survey. Members of the support group (N = 200) were sent an email inviting them to participate in the study. Those who agreed to participate were emailed a link to the Survey Monkey online survey. Seventy-seven initially completed the questionnaire but only sixty-six women aged 35 years and older who had used ART when aged 35 or older fitted the survey criteria. Over half the women were aged 40 years or older. Data from nine participants was excluded from the analysis as participants were younger than 35 when they had accessed ART. Most women were at an age when fertility is likely to be compromised, as the mean age was 40.74 years, and represent a cross section of older women accessing ART (Hughes et al., 2005; Leader, 2006; Menken, Trussell, & Larsen, 1986; Prysak et al., 1995; van Noord-Zaadstra et al., 1991). Women in the support group had engaged with ART after their 32nd birthday. Taking into consideration that some researchers consider that fertility declines from the age of 32 years, all were potentially in the range of some fertility decline.

### **5.4.2 Instrument.**

The survey questions investigated women's experiences while undertaking ART and their expectations of the technology (see Appendix 1). Some participants had achieved a pregnancy, and some had given birth and some had not achieved either of these goals at the time of the survey. Some women had completed their treatment, some were still involved in treatment, and some were planning further cycles. The number of cycles undertaken was not available, as ethical clearance did not cover clinical data on the aetiology of infertility and data on cycle outcomes. Participants were not asked about clinical information as it could not be verified and participants may have an inaccurate

recall of their ART treatment (Kessels, 2003). Responses reflected the medical, emotional and psychological aspects surrounding engagement with ART.

The survey contained either multiple-choice format or Likert scale questions (N = 31) with two open-ended questions. Open questions allowed participants to describe their own experiences and to provide a greater depth of information than permitted by the questionnaire, (Carr, Chadwick, Eardley, & Page, 2012). Questions were framed around established and peer-reviewed theoretical frameworks that are used widely and have been reviewed in the literature on health topics similar to those explored in this research (Davidson & Goldenberg, 2003; O'Connor et al., 1999; Siminoff, Ravdin, & Colabianchi, 2000). A small group of women (N = 36) chose to expand their story on the last page of the survey where a section for further comments was provided. Additional comments were optional, and these are discussed in Chapter 9.

The following peer-reviewed instruments were initially intended for inclusion in Survey B; however not all items for the instruments for the Fertility Problem Inventory (FPI) and Decisional Conflict Scale (DCS) instrument were used as the response number was statistically low and psychometric properties could not be properly determined. However, some questions from the FPI and DCS were included as they related intimately to the research questions. Questions from the following instruments were included in Survey B:

- a) The Fertility Problem Inventory (FPI)
- b) The Decision Regret Scale (DRS)
- c) The Decisional Conflict Scale (DCS)

a) The FPI provides a reliable measure of perceived infertility-related stress. ART treatment and the desire for parenthood reflect social concerns, which are central to distress (Newton, Sherrard, & Glavac, 1999). The scale provides validity, measurement and structural invariance (Moura-Ramos, Gameiro, Canavarro, & Soares, 2012). This research included the ten questions regarding social concerns from the 46 questions in the instrument. The remaining 36 questions exploring sexual concerns and concerns about relationship stability which were not applicable to the research questions. The responses to the ten issues relating to social concerns were analysed and compared and contrasted with the qualitative data from Group B and Group D.

b) The DRS comprises six items that explore healthcare decision regret at a given point in time (O'Connor, 1993). The DRS is a 5-item scale that asks subjects to reflect on a

particular decision and then rate each item on a 5 point scale from 1 (strongly agree) to 5 (strongly disagree). A total DRS score is derived from reverse scoring items 2 and 4, calculating a mean score, and transforming the average scores by subtracting 1 and then multiplying by 25. The total DRS scores range from 0 to 100 and higher scores indicate a greater appraisal of decision regret (O'Connor, 1993). The scale is measured using a self-reported Likert scale with 0 equating to no regret and 100 equating to highest regret (Davidson & Goldenberg, 2003]. The DRS (Brehaut, 2003) was used to measure ART decision regret and to assess which decisions result in regret if the outcome is not what the individual envisaged. This scale has been used previously to assess decisions made by cancer patients about whether to access treatment after diagnosis (Davidson & Goldenberg, 2003). The DRS was used to evaluate fertility-related decisions in young women diagnosed with early stage breast cancer (Peate et al., 2012). The DRS has a high internal reliability consistency with a measure of Cronbachs coefficient  $\alpha$  of 0.81-0.92 (Brehaut et al., 2003; O'Connor, 1993).

c) The DCS (O'Connor, 1995) is a conflict scale to measure what the participant feels it is like to live with the consequences of choice concerning health decisions. This scale examines choices perceptions of risks and benefits, decision-making and levels of emotional stress. The DCS comprises 16 items that measure decisional conflict regarding uncertainty about medical action and healthcare users' perceptions about their decisions. The scale quantifies factors that contribute to uncertainty during deliberation before and after an ART cycle of treatment. This research used 13 items covering the informed, support, uncertainty and effective decision subscales (O'Connor, 1993). Katapodi, Munro, Pierce and Williams (2011) tested the validity of the DCS and demonstrated that all 16 validated questions are necessary and Tabachnick and Fidell (Tabachnick & Fidell, 2007) suggest at least 300 respondents are required for factor analysis. However, 13 of the 16 questions were analysed with descriptive statistics.

Study specific questions were also used to assess social capital by exploring linkages between individuals, social relationships, environment and social networks to which they feel connected (Germov, 2005). This was evaluated using features from the socio-ecological framework of Bronfenbrenner, which is conceptual in nature, and is not operationalized into specific instruments and scales (Bronfenbrenner, 1977, 1979, 1986). The ecological systems theory suggests that different levels of social exposure influence human development. Social connections closer to the individual, such as immediate family and peers, would have greater influences than those more distant such as media, social

institutions or neighbours. This framework is used to examine the proximity of personal relationships to women's decisions regarding childbearing and their knowledge of fertility and ART.

The following five key questions were asked of the participants. These questions were also asked of participants in Group C.

Question 1) Would you choose either; women's career and work, educational attainment, financial security, health or partnering relationship as the primary reason women delay motherhood until they are older?

Question 2) Which age range; younger than 35 years, 35–39 years of age, or 40 years or older, signals a significant drop in a woman's fertility and ability to conceive?

Question 3) Are women aged 35 years or older likely or unlikely to get pregnant using ART?

Question 4) Are women aged 35 years or older likely or unlikely to have a healthy baby using ART?

Question 5) Do you feel that media, including magazines and current affairs programmes, does or does not portray IVF as being successful for older women?

#### **5.4.3 Data Analysis.**

Responses to the online survey were recorded on the password-protected Survey Monkey site ([www.surveymonkey.com](http://www.surveymonkey.com)) and deleted from the web server after downloading; these anonymous responses were saved as a CSV file. Quantitative data were coded then analysed using Version 19 of the Statistical Package for the Social Sciences (SPSS)(IBM, 2010). SPSS excluded missing data from the analysis as not all participants completed every single item. Missing data reduces the available sample size and consequently data becomes less powerful (de Vaus, 1995). Responses were broken down into two groups; aged 35-39 years and 40 years of age or older (Bianco, 1996; Bornstein et al., 2006; Damario et al., 1999; Gilbert et al., 1999).

The responses for Questions 3 (What is the likelihood of women aged 35 years or older to get pregnancy using ART?) and 4 (What is the likelihood of women aged 35 years or older to have a healthy baby using ART?) were condensed with response "not likely" and 2 collated to "not likely", 3 and 4 to "unlikely", 5 and 6 to "neither unlikely nor likely", 7 and 8

to “likely” and 9 and “very likely”. Where appropriate, categories were collapsed due to the small sample size to improve the accuracy of the reporting, which did not affect the integrity of the data. As Burton (2004) suggests, collapsing categories for a small number of respondents will allow a more accurate and robust analysis. Collapsing the data allows patterns in the data to be highlighted which otherwise would not stand out (de Vaus, 1995).

Pearson’s chi-squared variance and frequency were used predominantly to analyse relationships in the data. Ordinal data were examined using the chi-squared test of variance. A chi-square analysis requires the count in the cells of the contingency tables to exceed five. Some of the analysis, when broken down by age, had cells that had a count of less than five, and if 80% of the expected frequencies did not exceed five a chi-squared analysis for trend was used. In addition to the research questions, relationships between demographics, childbearing decisions, social and psychological factors and women’s expectations of ART were examined.

## **5.5 Group C: Community Group Study**

### **5.5.1 Participants.**

The Queensland Social Survey Community Survey (QSSCS) in 2008 (Survey C), included 1243 adults (aged 18–83 years) residing in Queensland. The 2008 Queensland Social Survey (QSS08) was the fourth annual state wide survey administered by the Institute for Health and Social Science Research (IHSS) at Central Queensland University in Rockhampton, Australia (Population Research Laboratory for Social Science Research, 2008). The Population Research Laboratory (PRL) within the IHSS, holds databases of Queensland phone numbers, which are merged and checked for duplications or deletions before each survey sample.

The study was conducted using computer-assisted telephone interviewing (CATI) by the PRL testing laboratory using trained telephone interviewers. The PRL limited the number of questions for this research to five questions as part of a collaborative survey with other researchers also submitting questions in their area of interest. The 2008 QSS sampling, of which the survey was a part, was drawn from the telephone database by a computer program designed to select, with replacement, a simple random sample of phone numbers. The target population designated for telephone interviewing was persons 18 years or older who at the time of the survey were living in a dwelling in Queensland that

could be contacted by direct-dialled, land-based telephone service, which was the accepted laboratory control for conducting the research. One adult member of each household was interviewed.

The opportunity to be part of this larger CATI study allowed data to be gathered from over 1243 individuals within Queensland and produced substantial data from a broad cross-section of the community. The response rate was 37.07%, cooperation rate was 38.19%, contact rate was 97.78%, and the refusal rate was 55.82% as per the QSS08 data. Data were gathered from individuals who ranged in age from 18 to 83 years with a mean age of 51.6 years. Males comprised 50.1 % of respondents; 80% of the participants were Australian born. Most (64.9%) had up to 14 years of education, and 34.5% had 15 years or more of education. Due to financial limitations of the CATI study, the researcher was limited to five questions as outlined in 5.5.2.

### **5.5.2 Questions.**

The QSS08 survey consisted of three components relevant to this research, and responses to sections (b) and (c) were used in this study:

- (a) A standardised introduction
- (b) Standard demographic questions
- (c) Five questions relating to the this research as outlined below:

Five research questions that were posed to the participants .The questions related to reasons for delaying childbearing, beliefs of the age of women's fertility decline, hopes of the success rate for women aged 35 years and older and ideas about the media's influence on success rates for ART.

The questions were:

Question 1) Would you choose either; women's career and work, educational attainment, financial security, health or partnering relationship as the primary reason women delay motherhood until they are older?

Question 2) Which age range; younger than 35 years, 35–39 years of age, or 40 years or older, signals a significant drop in a woman's fertility and ability to conceive?

Question 3) Are women aged 35 years or older likely or unlikely to get pregnant using ART?



Question 4) Are women aged 35 years or older likely or unlikely to have a healthy baby using ART?

Question 5) Do you feel that media, including magazines and current affairs programs, does or does not portray IVF as being successful for older women?

Data were analysed with SPSS as described in 5.2.3. Responses to Questions 3 and 4 were condensed for reporting as outlined earlier. Data were further analysed according to gender because men and women may have different perceptions of technology and a different level of trust in new technology (Wajcman, 2004) and they may have different understandings of female reproduction and fertility (Daniluk & Koert, 2013).

## **5.6 Group D: Interview Study**

The researcher formulated a recommended question script for the semi-structured interviews and prompts for the interview facilitator. This interview script guide ensured maximum use of the interview time and helped to keep interviews focused, while allowing the systematic interviewing of the participants (Loftland & Loftland, 1984). The average duration of the interviews was one hour. A semi-structured interview gave control and structure to the conversation, and flexibility to develop rapport and empathy with the participant, resulting in richer data (Smith & Osborn, 2008).

An experienced and neutral facilitator rather than the researcher conducted the interviews for three reasons. Firstly, a neutral facilitator limits the possibility that the interviewer could be biased because qualitative data are less structured and can be criticised on the basis of interviewer bias (Johnson, 1997). Secondly, as individuals may attend a number of infertility clinics, there was a chance that the researcher, when employed at a Queensland infertility clinic, may have had previous contact with an interviewee, which could be perceived as a potential bias. Panucci and Williams (2010) point out that interviewer bias is more likely when the interviewer knows the interviewee's disease status. Thirdly, the researcher wished to avoid any assumption that they may have unknowingly led the interview in a predetermined direction.

The researcher was concerned that the effect of the researcher's presence may have had on the participant's responses. Researchers, focusing on their hypothesis, may send out unwanted signals to interviewees, whereas independent interviewers are not subject to subconscious tendencies (Clarke, Sprostan, & Thomas, 2003). An independent interviewer was viewed as a necessity as the researcher was required to provide a reliable reflection

of participant views without the participant perceiving that the questions were leading the interviewee to a pre-determined end (Neuman, 2003b). Despite being aware of reflexivity to oppose researcher bias, the researcher did not wish to be seen as steering the interviewees towards the researchers preferred outcomes as interviewers should not reveal their opinions, either verbally or non-verbally (Neuman, 2003a).

Through constant comparison, thematic categories were identified and evaluated and build into a coherent model of the women's stories (Lincoln & Guba, 2000). The validity of interviews was monitored by external audit and triangulation of the interviews by the researcher and a neutral supervisor to ensure an unbiased assessment (Cresswell & Miller, 2000). Triangulation also permitted convergence of the interview data and the short answer responses from Group B by merging these in the overall interpretations of responses in the discussion (Cresswell, Fetters, & Ivankova, 2004). Validity was also established by the researcher through a rigorous review of the data to ensure that the "constricts, categories, explanations and interpretations make sense" (Patton, 1990: 239).

### **5.6.1 Participants**

Face-to-face interview participants were women aged 35 years and older. Participants were registered patients of another Brisbane infertility clinic and were invited to participate in the study by a flyer distributed to patients. Infertility nurses offered flyers to patients and flyers were displayed at the clinic reception desk for one month. Six women agreed to participate in the research: five in a face-to-face interview and one woman (located in Central Queensland) by telephone.

### **5.6.2 Interview Questions**

The 12 interview questions followed the five standard questions used in the QSS08 survey. The interviews were audiotaped, transcribed and analysed for themes:

- 1) Tell me who you are, and your position in your IVF journey: started or not, how many cycles undertaken, any pregnancies or births, and how many years of trying for a natural conception before ART.
- 2) What are some personal reasons why you are having a family at this stage of your life? What do you think about women looking to childbearing when aged 35 or older?
- 3) When do you believe a woman's fertility start to decline?

- 4) How would you rate the chance for a woman aged 35 or older to have a pregnancy?
- 5) How would you rate the chance for woman aged 35 or older to have a live birth?
- 6) What perception do you think the media gives women of the success of ART? Do you think media stories influence women's timing of childbearing?
- 7) Do you think the marketing information supplied from infertility clinics shape women's impression of IVF technology and success rates?
- 8) Your expectation of ART technology, and have your expectations been reached?
- 9) Your experiences of going through ART treatment; was that different to your expectation before you started ART?
- 10) What do you think the success rates of ART were before you accessed the clinic and has that changed now?
- 11) Taking your experiences into account, do you have advice for other women about the ideal age to have a child?
- 12) Do you think it is difficult for women to stop IVF cycles if they have not had a baby? What factors could influence their decision to stop?

### **5.6.3 Data analysis**

## **5.7 Ethical clearance for the research**

Ethical clearance for Group A and Group B research was gained from the Central Queensland Ethics Committee (Ethics Approval No H06/07-137) and the Infertility Clinic's Humanities and Ethics Committee (See Appendix 2). The University of Queensland and the Central Queensland University, due to the highly emotional subject matter of the research, required ethical approval for the surveys and interviews. Studies in this area, and in particular for women whose ART treatment was unsuccessful, can be psychologically difficult for some participants and may have adverse consequences for some women.

Ethical clearance for Survey C was granted by the Human Ethics Research Review Panel at CQUniversity Project: H08/05-020, Queensland Social Survey 2008. Group D interviews received ethical approval by the Behavioural & Social Sciences Ethical Review

Committee at the University of Queensland (Project: 2011000456) (see Appendix 2). The design and conduct of the research was heavily influenced by the sensitivity surrounding issues of infertility and the personal stress that ART can place on individuals, particularly if no conception or live birth resulted. Participants had the option not to participate or to discontinue participation at any stage. Counselling support for participants was freely available from the infertility clinics psychologists if requested. Contact information for Lifeline and the infertility clinic was supplied in the participant information sheet. No requests for counselling support were received by the researcher or research supervisor over the duration of the research.

## **5.8 Data Management**

Hard copy data were kept in a locked filing cabinet in the office of the investigator. Data on the principle researcher's computer were password protected following the requirements of the NHMRC Ethical Guidelines for Human Research (NHMRC, 2014). Data will be retained for five years in keeping with NHMRC guidelines. After this period, hard copy data will be shredded, and the computer files deleted.

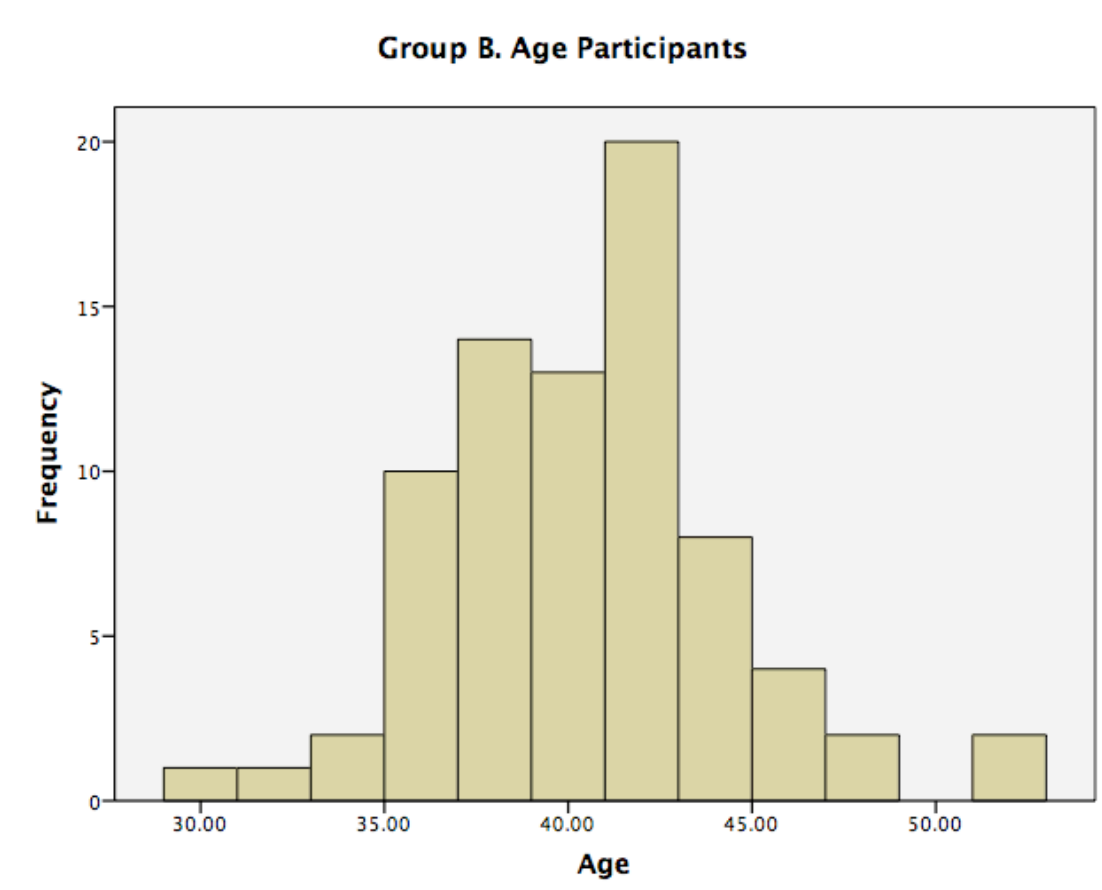
## **Chapter 6: Group B Data – Support Group**

### **6.1 Introduction**

This chapter reports data from Group B collected from participants in the Support Group. The method of data collection and the methodology are described in Chapter 5. Women were asked about influences, beliefs, experiences and expectations relating to starting, continuing and stopping ART. For the purpose of more meaningful analysis, some responses were further divided into two categories based on age groups; 35–39 years of age and 40 years or older. Although 77 responses were received, the responses from nine participants were excluded as either their age at the time of the survey was younger than 35 years, or their engagement with ART occurred when younger than 35 years.

## 6.2 Demographics

The participants (N = 68) were registered female patients of a Queensland infertility clinic. As shown in Figure 6.1, participants ranged in age from 35 to 52 years with a mean age of 40.7 years. (SD=3.93)



**Figure 6-1 Group B Participant Ages**

Most participants 94% (45/48) were or had been in a partnered relationship including two women who were separated, divorced or widowed, and seven women were not in a currently partnered relationship. Three women were in a same-sex relationship. Most participants (41/53) were in a relationship for longer than five years. Half the women agreed that women should be in a stable relationship when having children. Two-thirds of women were currently in the same relationship as when they had undertaken treatment. As anticipated, three-quarters (49/68) of participants were Australian born.

Table 6.2 shows that the educational attainment of participants was higher and more women had tertiary qualifications than their mothers. Similarly, the participants were more

likely to be in employment and less likely to primarily work in the home than their mothers. Ninety-three percent of the women's mothers had their first child when aged younger than 30 years and 7% when aged 31–39 years of age. 35% of women (22/62) had naturally conceived a baby before using ART for another child. For around one-fifth of these (12/62), a baby was born using ART.

**Table 6-1 Group B and Mother's Education and Employment**

Education and Employment/Activity	Participants	Participant's mothers
Secondary level education	11 (14.4)	44 (61.1)
Trade/Diploma qualification	21 (27.6)	15 (20.9)
Tertiary Education	26 (34.2)	9 (12.5)
Postgraduate education	18 (23.7)	4 (5.6)
Full-time employment	27 (36.0)	17 (22.4)
Part-time employment	22 (29.3)	14 (18.4)
Household duties	20 (26.7)	44 (57.9)
Carer	4 (5.3)	0
Student	2 (2.7)	0
Retired from paid work	0	1 (1.3)
Other	3 (4.0)	0

*Note.* Number (%)

### 6.3 Treatment Status

As discussed in Chapter 4, participants were predominantly of an age associated with declining fertility due to age-related infertility. Responses were sought from women aged 35 and older. The age distribution at time of survey was: 35–39 years (39.7%), and 40 years and older (62.3%). Of the 64 respondents, 25% of participants were currently having ART treatment, 30% had used ART within the last 12 months, 25% had ART treatment within two to three years of the survey, 18.5% had ART treatment within three or more years and one participant was intending to start ART as shown in Table 6.2. Some of the participants had conceived a pregnancy unassisted by ART but over half of these had spontaneously miscarried. The participants were asked about the outcome of their treatment as women may have had multiple treatment cycles with more than one outcome. Tables 6.3.1 to 6.3.7 details the treatment outcomes.

**Table 6-2 Group B: Treatment Status**

Engagement with ART	35-39 years of age	40 years and older	Total
Currently using ART	9 (56.3)	7 (43.7)	16 (100.0)
Used ART within the last 12 months	8 (42)	11 (58)	19 (100.0)
Used ART within 2–3 years	7 (44)	9 (56)	16 (100.0)
Used ART over 3 years ago	3 (25)	9 (75)	12 (100.0)
Intending to use ART	0	1 (100)	1 (100.0)
Total for age groups	27 (42)	37 (58)	64 (100.0)

*Note.* Number (%)

#### 6.3.1 Group B treatment outcome – pregnancies.

Table 6.3 shows that 67% of participants had at least one pregnancy with 71.4% of those aged 35–39 years and 62.9% of those aged 40 years and older. The percentage of women

who had a pregnancy did not significantly differ between age groups,  $\chi^2(1, N = 55) = 0.266, p = 0.606$ .

**Table 6-3 Group B: At Least One Pregnancy**

At least one pregnancy	Yes	No	Total
35–39 years	15 (71.4)	6 (28.6)	21 (100.0)
40 years or older	22 (62.9)	12 (34.3)	34 (100.0)
Total	37 (67.3)	18 (32.7)	55 (100.0)

*Note.* Number (%)

### 6.3.2 Group B treatment outcome – births.

Table 6.4 shows over half of participants in both age groups had at least one live birth. The percentage of women who had a birth did not significantly differ between age groups,  $\chi^2(1, N = 50) = 0.127, p = 0.721$ .

**Table 6-4 Group B: At Least One Birth**

At least one birth	Yes	No	Total
35–39 years	12 (63.1)	7 (36.9)	19 (100.0)
40 years or older	18 (58.1)	13 (41.9)	31 (100.0)
Total	30 (60.0)	20 (40.0)	50 (100.0)

*Note.* Number (%)

### 6.3.3 Group B treatment outcome – pregnancy loss.

Table 6.5 shows half of the participants in both groups had a pregnancy that did not continue. The percentage of women who had a pregnancy loss did not significantly differ between age groups,  $\chi^2(1, N = 47) = 0.013, p = 0.909$ .



**Table 6-5 Group B: Pregnancy Loss**

Pregnancy loss	Yes	No	Total
35–39 years	9 (50.0)	9 (50.0)	18 (100.0)
40 years or older	15 (51.7)	14 (48.3)	29 (100.0)
Total	24 (51.1)	23 (48.9)	47 (100.0)

*Note.* Number (%)

#### 6.3.4 Group B treatment outcome – women undertaking ART.

Table 6.6 shows around half of applicable participants, more aged 35–39 years than aged 40 years or older, were still using ART to have a child. The percentage of women who were still using ART did not significantly differ between age groups,  $\chi^2(1, N = 42) = 1.14, p = 0.286$ .

**Table 6-6 Group B: Still Undertaking ART**

Still trying for a child	Yes	No	Total
35–39 years	13 (68.4)	6 (31.6)	19 (100.0)
40 years or older	12 (46.2)	11 (42.3)	23 (100.0)
Total	25 (59.5)	17 (40.5)	42 (100.0)

*Note.* Number (%)

#### 6.3.5 Group B treatment outcome – still undertaking ART until successful.

One-half of the 38 participants were continuing ART with until they had a baby as shown in Table 6.7. Chi-square analysis between still undertaking ART until successful and the two age groups was not significant,  $\chi^2(2, N = 38) = 0.217, p = 0.897$ . One-third were unsure of their decision to stop ART.

**Table 6-7 Survey Group B: Keep Trying Until Have a Child**

Keep trying for a child	Yes	No	Unsure	Total
35–39 years	3 (21.4)	6 (42.9)	5 (35.7)	14 (100.0)
40 years or older	5 (16.1)	12 (38.7)	7 (22.6)	34 (100.0)
Total	8 (21.0)	18 (47.4)	12 (31.6)	38 (100.0)

*Note.* Number (%)

### 6.3.6 Group B treatment outcome – stopped ART and successful birth.

Table 6.8 shows 32.6% of applicable participants of all ages had stopped ART as they had a live birth, and around half had stopped without having a baby. The relation between these variables was not significant,  $\chi^2(2, N = 46) = 2.895, p = 0.235$ . One-fifth were unsure of their decision to stop ART.

**Table 6-8 Group B: Stopped ART and Successful Birth**

Stopped ART and have child	Yes	No	Unsure	Total
35–39 years	7 (41.2)	5 (29.4)	5 (29.4)	17 (100.0)
40 years or older	8 (27.6)	16 (55.2)	5 (17.2)	29 (100.0)
Total	15 (32.6)	21 (45.6)	10 (21.8)	46 (100.0)

*Note.* Number (%)

### 6.3.7 Group B treatment outcome – stopped ART as unsuccessful.

One-fifth of participants had stopped ART and did not conceive, as shown in Table 6.9. Chi-square analysis for trend between stopped ART and did not have a baby and the two age groups was not significant,  $\chi^2(1, N = 33) = 2.584, p = 0.108$ , the decision to stop ART was not dependent on age group. One-sixth were unsure of their decision to stop ART.

**Table 6-9 Group B: Stopped ART as Unsuccessful**

Stopped ART and do not have child	Yes	No	Unsure	Total
35–39 years	2 (20.0)	8 (80.0)	0	10 (100.0)
40 years or older	4 (17.4)	14 (60.9)	5 (21.7)	23 (100.0)
Total	6 (18.1)	22 (66.7)	5 (15.2)	33 (100.0)

*Note.* Number (%)

## 6.4 Beliefs and Decisions on ART and Childbearing

### 6.4.1 Decisions surrounding ART.

The Decision Regret Scale (O'Connor, 2003) as discussed in Chapter 5.4.2 measures distress or remorse after a health care decision, as shown in Table 6.10. Participants were asked five questions of the instrument regarding their decision to delay childbearing. The scale has five items and is scored from 0–100, and a higher score indicates less regret about the decision to delay childbearing. As described in Chapter 5, the scale comprised five questions that are scored. Questions one, three and five are scored with a result of 0 indicating high regret and 100 indicating no regret. Questions two and four are reverse scored with a score of 0 scoring no regret and 100 high regret. The women were somewhat divided whether delaying childbearing was; the right decision, if they regretted their decision, if they would make the same decision again, if it had done them harm and if it was a wise decision.

**Table 6-10 Group B: Decision Regret Scale on Decision to Delay Childbearing**

Decision	Agree	Disagree	Unsure	Strongly Agree	Strongly Disagree	Total Score
It was the right decision	6	7	7	11	8	39 (42.3)
I regret the decision that was made	4	10	7	11	4	36 (44.3)
I would go for the same choice if I had to do it over again	4	11	5	6	9	35 (49)
The choice did me a lot of harm	4	9	8	7	8	36 (53.3)
The decision was wise	2	12	5	7	7	33 (57.5)

*Note.* Number ( Score)

Questions about decisions to use ART were modelled on the Decisional Conflict Scale. As not all the questions from the instrument were used, the instrument cannot be reported, however responses follow in Table 6.11–6.13. Table 6.11 shows that most participants did not find the decision to use ART hard, most were sure of their decision and ART was the best choice for them.

**Table 6-11 Group B: Decision to use ART**

Decision to use ART	Yes	No	Unsure	Total
Decision was hard to make	15 (27.8)	39 (72.2)	0	54 (100.0)
Not sure what to do in this decision	12 (23.1)	35 (67.3)	5 (9.6)	52 (100.0)
Clear what choice is best	35 (67.3)	13 (25.0)	4 (7.7)	52 (100.0)

*Note.* Number (%)

Table 6.12 shows that most participants were aware of the choices they had in ART, and they were aware of risks and benefits.

**Table 6-12** Group B: Risks and Benefits of ART

Choice to use ART	Yes	No	Unsure	Total
Aware of choices in ART	41 (75.9)	10 (18.5)	3 (5.6)	54 (100.0)
Know the benefits of ART	44 (81.5)	8 (14.8)	2 (3.7)	54 (100.0)
Know the risks of ART	40 (74.1)	10 (18.5)	4 (7.4)	54 (100.0)

*Note.* Number (%)

Table 6.13 shows most participants felt they had made an informed choice to use ART, would stick to their decision, the decision was important to them, and they were satisfied with their decision.

**Table 6-13** Group B: Effective Decision Making

Decision satisfaction	Yes	No	Unsure	Total
Feel made informed choice	45 (83.3)	6 (11.1)	3 (5.6)	54 (100.0)
Decision important	48 (94.1)	2 (3.9)	1 (2.0)	51 (100.0)
Stick with decision	44 (86.3)	2 (3.9)	5 (9.8)	51 (100.0)
Satisfied with decision	47 (88.7)	2 (3.8)	4 (7.5)	53 (100.0)

*Note.* Number (%)

### 6.4.2 Beliefs about ART.

Table 6.14 shows chi-square test between pregnancy confidence and two age groupings and was significant,  $\chi^2(2, N = 64) = 7.78, p = .020$ . Women aged 35–39 years had a stronger belief they would get pregnant than the women aged 40 years or older.

**Table 6-14** Group B: Beliefs about Getting Pregnant by Age Group Response

Belief about getting Pregnant	Disagree	Unsure	Agree	Total
35–39 years	0	6	19	25
		(24.0)	(76.0)	(100.0)
40 years or older	9	11	19	39
	(23.1)	(28.2)	(48.7)	(100.0)
Total	9	17	38	64
	(14.0)	(26.5)	(59.5)	(100.0)

*Note.* Number (%)

Table 6.15 shows there was no difference between the two age groups on the assumption that the quality of their oocytes was problematic. Chi-square test for trend was not significant,  $\chi^2(1, N = 61) = 0.1699, p = .680$ .

**Table 6-15** Group B: Oocyte Quality

Belief oocyte problem	Disagree	Unsure	Agree	Total
35–39 years	10	2	14	26
	(38.5)	(7.7)	(53.8)	(100.0)
40 years or older	18	3	14	35
	(51.4)	(8.6)	(40.0)	(100.0)
Total	28	5	28	61
	(45.9)	(8.2)	(45.9)	(100.0)

*Note.* Number (%)

Participants were asked to reflect on the beliefs they held about ART. Responses are shown in Table 6.16. Most participants agreed that media success stories of ART do not depict the experiences for most women, they were confident of a pregnancy, women need to be in a stable relationship before children, and ART does not guarantee a baby. The majority of women disagreed that ART allows women to delay childbearing, having regular menstrual cycles allows pregnancy regardless of age, having a child later in life is trying to

have the best of everything, and it is not possible to have a successful career and a family. They were equally divided whether mixing motherhood and career is a result of social pressure.

**Table 6-16 Group B: Beliefs regarding ART Before Starting Treatment**

Beliefs	Disagree	Unsure	Agree	Total
ART success media stories not representative of ART users	15 (25.0)	7 (11.7)	38 (63.3)	60 (100.0)
Confident that ART will ensure pregnancy	5 (9.8)	2 (3.9)	44 (86.3)	51 (100.0)
ART allows women aged 35 and older to have children	36 (60.0)	2 (3.3)	22 (36.7)	60 (100.0)
Women need to be in a stable relationship before children	24 (40.0)	4 (6.7)	32 (53.3)	60 (100.0)
Regular menstrual cycles allow childbearing regardless of age	46 (76.7)	3 (5.0)	11 (18.3)	60 (100.0)
Mixing motherhood and career due to social pressure	27 (45.8)	6 (10.1)	26 (44.1)	59 (100.0)
Child in midlife trying for best of everything	50 (84.7)	2 (3.3)	7 (11.9)	59 (100.0)
Not possible for successful career and family life	49 (84.5)	2 (3.4)	7 (12.1)	58 (100.0)
ART no guarantee of a baby	5 (8.3)	2 (3.3)	53 (88.4)	60 (100.0)

*Note.* Number (%)

Women's obstetrician or gynaecologist and self-education were strong sources of information on ART. Some information was sourced from public health information, internet sites, television, newspapers, friends, family, colleagues and community knowledge on ART as shown in Table 6.17. Educational institutions were the least informative source.

**Table 6-17 Group B: Sources of Information regarding ART**

Sources of information	Strong Influence	Some Influence	No Influence	Total
Education from school /university	2 (9.5)	1 (4.8)	18 (85.7)	21 (100.0)
Self education	17 (77.4)	4 (18.1)	1 (4.5)	22 (100.0)
Public Health Information	3 (18.8)	12 (75.0)	1 (6.2)	16 (100.0)
Family	3 (16.7)	10 (55.5)	5 (27.8)	18 (100.0)
Friends	6 (27.2)	13 (59.1)	3 (13.7)	22 (100.0)
Work colleagues	2 (18.2)	9 (81.8)	0	11 (100.0)
Obstetrician/ Gynaecologist	43 (100.0)	0	0	43 (100.0)
Newspapers	3 (33.3)	6 (66.7)	0	9 (100.0)
Women's magazines	5 (8.3)	30 (50.0)	25 (41.7)	60 (100.0)
Television	0	8 (80.0)	2 (20.0)	10 (100.0)
Internet sites	4 (33.3)	5 (41.7)	3 (25.0)	12 (100.0)
Community knowledge	4 (33.3)	7 (58.4)	1 (8.3)	12 (100.0)

*Note.* Number (%)

Table 6.18 shows views of media portrayal of ART for two age groups. Chi-square analysis for trend between media portrayal of ART and the two age groupings was not significant,  $\chi^2 (1, N = 54) = 0.138, p = .709$ , the groups were in agreement that the media portrays ART as successful for older women.



**Table 6-18 Group B: Media Influence**

Age	Yes	No	Unsure	Total
35–39 years	19 (90.4)	1 (4.8)	1 (4.8)	21 (100.0)
40 years or older	30 (90.9)	2 (6.1)	1 (3.0)	33 (100.0)
Total	49 (90.7)	3 (5.6)	2 (3.7)	54 (100.0)

*Note.* Number (%)

Table 6.19 shows chi-square test for trend between beliefs about fertility decline and the two age groupings and was not significant,  $\chi^2(1, N = 56) = 1.981, p = .159$ .

**Table 6-19 Group B: Beliefs on Age of Fertility Decline by Age Response**

Age	Declines from 34 years or younger	Declines from 35– 39years	Declines from 40 years or older	Total
35–39 years	14 (51.8)	13 (48.2)	0	27 (100.0)
40 years or older	0	25 (86.2)	4 (13.8)	29 (100.0)
Total	14 (25.0)	38 (67.9)	4 (7.1)	56 (100.0)

*Note.* Number (%)

Table 6.20 shows beliefs on the chance of pregnancy for women aged 35 years or older using ART for the two age groups. Chi-square analysis between chance of a pregnancy and the two age groupings was not significant,  $\chi^2(2, N = 56) = 0.373, p = .829$ .

**Table 6-20 Group B: Likelihood of Pregnancy for Women aged 35 and older using ART**

Age	Not Likely	Neither not likely or likely	Likely	Total
35–39 years	5 (23.8)	10 (47.6)	6 (28.6)	21 (100.0)
40 years or older	11 (31.4)	15 (42.9)	9 (25.7)	35 (100.0)
Total	16 (28.6)	25 (44.6)	15 (26.8)	56 (100.0)

*Note.* Number (%)

Table 6.21 shows beliefs on the chance of a healthy baby for women aged 35 years or older using ART between the age groups. Chi-square analysis between beliefs and the age groupings was not significant,  $\chi^2(4, N = 56) = 0.533, p = .766$ .

**Table 6-21 Group B: Likelihood of a Live Birth for Women aged 35 and older using ART**

Age	Not Likely	Neither not likely or likely	Likely	Total
35–39 years	5 (23.8)	9 (42.9)	7 (33.3)	21 (100.0)
40 years or older	11 (31.4)	15 (42.9)	9 (25.7)	35 (100.0)
Total	16 (28.6)	24 (42.8)	16 (28.6)	56 (100.0)

*Note.* Number (%)

Table 6.22 shows beliefs on their personal chance of pregnancy using ART between the two age groups. Chi-square analysis between expectations and the age groupings was not significant,  $\chi^2(4, N = 62) = 0.982, p = .612$ .

**Table 6-22 Group B: Personal Belief on a Pregnancy**

Belief of a pregnancy	Not Likely	Neither not likely or likely	Likely	Total
35–39 years	3 (11.1)	6 (22.2)	18 (66.7)	27 (100.0)
40 years or older	5 (14.3)	11 (31.4)	19 (54.3)	35 (100.0)
Total	8 (12.9)	17 (27.4)	37 (59.7)	62 (100.0)

*Note.* Number (%)

Participants were asked to estimate their personal chance of a pregnancy between the two age groups, as shown in Table 6.23. Most women rated their chance of pregnancy at 40–60% or less.

**Table 6-23 Group B: Personal Beliefs on Chance of a Pregnancy**

Age	0–20%	20–40%	40–60%	60–80%	80–100%	Total
35–39 years	3 (23.1)	5 (38.4)	3 (23.1)	1 (7.7)	1 (7.7)	13 (100.0)
40 years or older	11 (61.1)	4 (22.2)	3 (16.7)	0	0	18 (100.0)
Total	14 (45.2)	9 (29.0)	6 (19.4)	1 (3.2)	1 (3.2)	31 (100.0)

*Note.* Number (%)

### 6.4.3 Timing of childbearing.

Participants were asked why women delay, childbearing until midlife. Five possible options, as suggested by the literature, were given to the participants and they were asked to choose one option, which they believed was the main reason for delaying childbearing. Results are shown in Table 6.24. Most participants selected the option of 'lack of a partner' as the main reason women are delaying childbearing until midlife.

**Table 6-24 Group B: Main Reason why Women Delay Childbearing**

Reasons for delaying childbearing	Response
Lack of a relationship partner	35 (63.6)
Career or work	12 (21.8)
Financial security	5 (9.1)
Health issues	3 (5.5)
Furthering Education	0
Total	55 (100.0)

*Note.* Number (%)

Table 6.25 shows chi-square test for trend between reasons for delaying and the two age groupings, and was not significant,  $\chi^2(1, N = 55) = 0.004, p = .949$ .

**Table 6-25 Group B: Delaying Childbearing by Age**

Age	Lack of partner	Career or work	Financial Security	Health	Education	Total
35–39 years	12 (57.1)	5 (23.9)	2 (9.5)	2 (9.5)	0	21 (100.0)
40 years or older	23 (67.6)	7 (20.6)	3 (8.9)	1 (2.9)	0	34 (100.0)
Total	35 (63.6)	12 (21.8)	5 (9.1)	3 (5.5)	0	55 (100.0)

*Note.* Number (%)

Table 6.26 shows current views on having a child. One-third of the women suggested that they were trying ART to do all they could to have a child and they would have had a child earlier but they were not in a supported partnered relationship.

**Table 6-26 Group B: Current Decision to have a Child**

Current Decision to have a Child	Response
Tried IVF to do everything possible to have a child	19 (35.2)
Would have had children earlier but not in a supported partnered relationship	14 (30.0)
Difficult to find a partner to share a family	7 (13.0)
Having a child is the current life focus	6 (11.1)
Waiting for financial security	6 (11.1)
Pursuing a career	1 (1.8)
Children not a life focus five years ago	1 (1.8)
Total	54 (100.0)

*Note.* Number (%)

Table 6.27 shows women's responses if, hypothetically, they would make the same decision to delay their childbearing for both age groups. Chi-square analysis between decision to delay childbearing and the two age groupings was not significant,  $\chi^2(1, N = 19) = 0.693, p = .405$ . Both groups disagreed that they would, hypothetically, make the decision to delay childbearing again.

**Table 6-27 Group B: Decision to Delay Childbearing by Age**

Age	Disagree	Agree	Total
35–39 years	6 (60.0)	4 (40.0)	10 (100.0)
40 years or older	7 (77.8)	2 (22.2)	9 (100.0)
Total	13 (68.4)	6 (31.6)	19 (100.0)

*Note.* Number (%)

#### 6.4.4 Heartache along the way.

As discussed in Chapter 4.7, ART treatment has been extensively documented in the literature as being a deeply emotional and stressful experience. Participants were asked whether the clinic provided sufficient social support for them. The Fertility Society of Australia requires ART clinics to offer psychological counselling for individuals before their first ART cycle. Some clinics offer continuous counselling, and 71% of women found the amount of counselling provided was adequate.

Women were asked if the clinic offered sufficient emotional support during their treatment, as shown in Table 6.28. Chi-square analysis for trend between emotional support and the two age groups was significant,  $\chi^2(1, N = 58) = 9.9351, p = .001$ . Women who conceived felt they had better emotional support than women who did not get pregnant.

**Table 6-28 Group B: Clinic Offered Adequate Emotional Support**

Pregnant after ART	Not offered emotional support	Offered emotional support	Unsure if offered emotional support	Total
No	6 (35.3)	8 (47.1)	3 (17.6)	17 (100.0)
Yes	7 (17.1)	34 (82.9)	0	41 (100.0)
Total	13 (22.4)	42 (72.4)	3 (5.2)	58 (100.0)

*Note.* Number (%)

Chi-square analysis for trend between a live birth and the clinic offering adequate emotional support was significant,  $\chi^2(1, N = 58) = 5.6105, p = .0179$ . As expected, most women who had a birth and half of those who did not have a birth agreed that they received emotional support, as shown in Table 6.29.

**Table 6-29 Group B: Had Birth and Clinic Offered Adequate Emotional Support**

Live Birth after ART	Not offered emotional support	Offered emotional support	Unsure if offered emotional support	Total
No	7 (31.8)	12 (54.6)	3 (13.6)	22 (100.0)
Yes	6 (18.7)	26 (81.3)	0	32 (100.0)
Total	13 (24.1)	38 (70.3)	3 (5.6)	54 (100.0)

*Note.* Number (%)

Additional questions were modelled on the Fertility Problem Inventory (Newton et al., 1999) as described in Chapter 5.4.2. The ten Social Concerns questions addressed the respondents' sensitivity to comments, reminders of infertility, feeling of social isolation and alienation from family or peers. Table 6.30 shows participants were mostly in agreement that they found holidays and celebrations difficult, they couldn't help comparing themselves with friends who had children, they had lots in common with friends who had children, and they felt like family and friends were leaving them out. Participants mostly disagreed that it did not bother them when asked questions about children, that family members didn't treat them differently, that family gatherings were difficult and that it was hard to spend time with friends who had children. Participants were equally divided when asked if they felt left behind by family and friends and feeling bothered when others talk about children.

**Table 6-30 Group B: Emotions Surrounding Children**

Emotions involving children	Agree	Disagree	Unsure	Total
Doesn't bother me when asked about children	20 (35.7)	33 (58.9)	3 (5.4)	56 (100.0)
Family members don't treat us differently	24 (42.9)	31 (55.3)	1 (1.8)	56 (100.0)
Celebrations and holidays difficult	33 (58.9)	19 (34.0)	4 (7.1)	56 (100.0)
Family get-togethers difficult	26 (46.4)	28 (50.0)	2 (3.6)	56 (100.0)
Can't help comparing myself to others with children	43 (76.8)	11 (19.6)	2 (3.6)	56 (100.0)
Lots in common with friends with children	31 (55.4)	22 (39.2)	3 (5.4)	56 (100.0)
Hard when with friends with children	24 (42.9)	30 (53.5)	2 (3.6)	56 (100.0)
Families with children make me feel left out	33 (58.9)	21 (37.5)	2 (3.6)	56 (100.0)
Feel left behind by family and friends	28 (50.0)	28 (50.0)	0	56 (100.0)
Not bothered if others talk about children	27 (48.2)	27 (48.2)	2 (3.6)	56 (100.0)

*Note.* Number (%)

## 6.5 Experiences of ART

All the women who were still trying for a pregnancy and 92% of women who were not trying for a pregnancy believed their clinician had explained the medical procedures in detail. Participants were asked about their emotional and psychological experiences while attending the infertility clinic by the provision of caring and supportive service. Table 6.31 shows most participants indicated that the clinic offered them emotional (91%) and psychological (67%) support and that they did not feel out of control during treatment (85%). They believed their clinician explained the medical procedures in sufficient detail (90%), explained all the treatment options (85%), informed them of drug side effects (76%), and the risks of, and options in, ART (75%).



**Table 6-31 Group B: Psychological Support during ART**

Psychological Support	Agree	Disagree	Unsure	N/A	Total
Clinician explained ART	51 (91.2)	4 (7.1)	1 (1.7)	0	56 (100.0)
Treatment options explained	49 (86.0)	5 (8.8)	3 (5.2)	0	57 (100.0)
Clinician gave ART options	49 (90.7)	4 (7.4)	1 (1.9)	0	54 (100.0)
Risks of ART explained	47 (83.9)	5 (8.9)	4 (7.2)	0	56 (100.0)
Drug effects explained	40 (75.5)	10 (18.9)	3 (5.6)	0	53 (100.0)
Clinic gave emotional support	50 (91.0)	4 (7.0)	1 (2.0)	0	55 (100.0)
Psychological support adequate	37 (67.3)	11 (20.0)	5 (9.1)	2 (3.6)	55 (100.0)
I felt out of control during treatment	9 (16.1)	47 (83.9)	0	0	56 (100.0)
Tried IVF to avoid future regret	33 (60.0)	13 (23.7)	2 (3.6)	7 (12.7)	55 (100)

*Note.* Number (%)    *N/A.* Not applicable

Participants did not feel that they needed more advice and information on ART, did not feel pressure from other people when making the decision to use ART, and were supported when making their choice, as shown in Table 6.32.

**Table 6-32 Group B: Decision Support**

Support Subscale	Yes	No	Unsure	Total
Need more advice and information on choices	15 (28.9)	33 (63.4)	4 (7.7)	52 (100.0)
Feel pressure from others making decision using ART	9 (17.3)	42 (80.8)	1 (1.9)	52 (100.0)
Support from others in making choice of ART	36 (69.2)	10 (19.3)	6 (11.5)	52 (100.0)

*Note.* Number (%)

Women who stopped ART when they had a child were asked if they had experienced emotional support. Table 6.33 shows chi-square analysis for trend between stopped ART with a live birth and the clinic offering emotional support was significant,  $\chi^2(1, N = 29) = 6.947, p = .008$ . Women who did not have a baby did feel supported but for those who had a baby, only one-quarter felt supported.

**Table 6-33 Group B: Comparing Stopped ART had Birth and Clinic Offered Emotional Support**

Stopped ART and birth	Not supported	Yes supported	Unsure if supported	Total
No	5 (25.0)	14 (70.0)	1 (5.0)	20 (100.0)
Yes	4 (57.1)	2 (28.6)	1 (14.3)	7 (100.0)
Unsure	1 (50.0)	0	1 (50.0)	2 (100.0)
Total	10 (34.4)	16 (55.2)	3 (10.4)	29 (100.0)

*Note.* Number (%)

Table 6.34 shows whether women felt assured by their clinicians that they would get pregnant, between the two age groups. Chi-square analysis between a decision to continue with ART after assurances and the two age groupings was significant,  $\chi^2(2, N = 59) = 9.444, p = .008$ . More women aged 35–39 years agreed their clinician assured them they were likely to get pregnant compared to women aged 40 years or older.

**Table 6-34 Group B: Doctor Assured Pregnancy by Age**

Age	Agree	Disagree	Total
35–39 years	18 (81.8)	4 (18.2)	22 (100.0)
40 years or older	12 (41.4)	17 (58.6)	29 (100.0)
Total	30 (58.8)	21 (41.2)	51 (100.0)

*Note.* Number (%)

Table 6.35 shows a series of questions to reflect on the participant’s experiences and expectations of ART. Most participants found their expectations of ART were met, were realistic, sympathetic service was provided, and their doctor understood their expectations. Most found their experiences with infertility challenging and half did find their experiences as difficult as they had expected. Overall most participants found their experiences to be ‘worth it.’

**Table 6-35 Group B: Expectations and Experiences**

Experiences and expectation	Response
The experience was worth it	51 (80.4)
My expectations of the technology were realistic	52 (78.9)
My expectations of the technology were met	51 (78.4)
My doctor understood my expectations	52 (77)
My expectations of sympathetic service were met	52 (77)
The experience was difficult	39 (66.7)
The experience as not as difficult as I expected	42 (42.9)

*Note.* Number (%)

## 6.6 Stopping ART

Table 6.36 shows that for participants who had ceased treatment, the main reasons for stopping ART was a birth or not conceiving. Emotional, financial and personal costs were selected by one-third of participants. Other than stopping as they had a baby, there is no dominant reason for discontinuing treatment. Clinics may not be aware that a woman has discontinued treatment, as patients leave clinics without notifying their clinicians.

**Table 6-36 Group B: Reasons for Stopping ART Treatment Response**

Reasons for stopping ART	Yes	No	Unsure	Total
I am pregnant	5 (20.8)	19 (79.2)	0	24 (100.0)
I have a baby	21 (70.0)	9 (30.0)	0	30 (100.0)
I have adopted a child	0	22 (100.0)	0	40 (100.0)
The emotional cost was too high	8 (36.4)	14 (63.6)	0	41 (100.0)
The financial cost was too high	11 (44.0)	14 (56.0)	0	42 (100.0)
I have decided to move to a childfree life	2 (9.6)	15 (71.4)	4 (19.0)	41 (100.0)
The treatment placed stress on personal relationships	8 (33.3)	15 (62.5)	1 (4.2)	43 (100.0)
I have had enough treatment	8 (34.8)	13 (56.5)	2 (8.7)	41 (100.0)

*Note.* Number (%)

As shown treatment costs may not be a major reason for stopping ART but may control the number of cycles. Table 6.38 demonstrates the relationship between cost limitations and pregnancy. Chi-square analysis between a pregnancy and treatment costs and was significant,  $\chi^2(1, N = 57) = 10.729, p = .001$ . Women who were not pregnant found the treatment costs limiting but those who were pregnant did not, clearly as they did not require a further cycle of ART.

**Table 6-37 Group B: Pregnancy and the Treatment Costs Limited the Number of Cycles**

Pregnant	Not limited by cost	Yes limited by cost	Total
No	6 (35.3)	11 (64.7)	17 (100.0)
Yes	32 (80.0)	8 (20.0)	40 (100.0)
Total	38 (66.7)	19 (33.3)	57 (100.0)

*Note.* Number (%)

As discussed in Chapter 2.8, the decision to continue or discontinue treatment is difficult for some women. Some women do not wish to experience regret after they discontinue treatment and for some, external factors may not allow them to continue ART cycles. The theory of anticipated decision regret (Tymstra, 1989, 2007) suggests that women will undertake ART to ensure they have done all possible to have a baby. This was supported by 68.8% (33/48) of the participants. Table 6.38 shows the relationship between decision regret and pregnancy. More women who were pregnant than not, supported avoiding disappointment.

**Table 6-38 Group B: Pregnancy and Regret Avoidance Response**

Pregnant after ART	Yes tried ART to avoid regret	Total
No	11 (35.5)	11 (100.0)
Yes	20 (64.5)	20 (100.0)
Total	31 (100.0)	31 (100.0)

*Note.* Number (%)

Table 6.39 shows whether the decision to continue ART was influenced by clinician's assurances. Chi-square analysis between their clinician encouraging them to continue treatment and the two age groups and was not significant,  $\chi^2(1, N = 43) = 1.1, p = .294$ .

**Table 6-39 Group B: Doctor Influenced Continuation of ART by Age**

Age	Yes	No	Total
35–39 years	7 (38.9)	11 (61.1)	18 (100.0)
40 years or older	6 (24.0)	19 (76.0)	25 (100.0)
Total	13 (30.2)	30 (69.8)	43 (100.0)

*Note.* Number (%)

Table 6.40 shows possible limitations to continuing ART. One-third of the participants aged 35–39 years responded that time and for one-third aged 40 years or older, oocyte quality were limitations for them. Younger women were more concerned about time constraints, and the older group were most concerned about their oocyte quality.

**Table 6-40 Group B: Personal Limitations to Continuing with ART Response**

Age	Time	Cost	Egg Quality	No Limits	Unsure if Limits	No Plans	Total
35–39 years	7 (35.0)	2 (10.0)	4 (20.0)	1 (5.0)	1 (5.0)	5 (25.0)	20 (100.0)
40 years or older	7 (27.0)	4 (15.4)	10 (38.4)	0	0	5 (19.2)	26 (100.0)
Total	14 (30.4)	6 (13.0)	14 (30.4)	1 (2.2)	1 (2.2)	10 (21.8)	46 (100.0)

*Note.* Number (%)

## 6.7 Summary

Data were collected from a small cohort of women (N=68), with an average age of 40.7 years, who had engaged with ART. Participants used ART because they were unable to conceive naturally and most women had, at least, one pregnancy that proceeded to a live birth. Of the pregnancies that were lost, there was no difference between the age groups on the rate of loss.

Most were in a stable relationship and educated to tertiary level and were in the workforce. Participants were mainly of an age where their fertility would be declining.

As they had some knowledge and experience of ART, most women suggested that fertility declined from the age of 35–39 years, and women aged 40 years or older were more knowledgeable of fertility decline. Some in the older age group suggested that fertility did not wane until women were older than 40 years. Women aged younger than 40 years were more confident of success than those aged over 40 years. Infertility clinicians boosted the confidence of a pregnancy and encouraged more women aged 35–39 years to continue with ART than those aged 40 years or older.

Most agreed that the lack of a relationship partner was the primary reason for women delaying childbearing, more so than career or work, financial security, health or furthering their education. There was a no significant difference between both age groups for this item.

Both age groups were equally unsure of the likelihood of pregnancy or birth for women 35 years or older. Half of the women were unsure if a birth was likely or not. However, they believed that they were likely to get pregnant, which is contrary to their uncertainty about the likelihood of a women aged 35 or older to be successful. Even though personally they were confident of a conception, few rated their chance of success at greater than 60%.

Many women who had stopped treatment either had a pregnancy or a baby, but some had stopped ART without having a baby. Women who were pregnant did not agree that financial reasons were limiting, but clearly those who were still trying, found costs to be a limiting factor.

Women thought their expectations of ART were realised. Their knowledge of ART was acquired primarily from their gynaecologist, media, and friends. Women aged 40 or older were more likely to be encouraged to try ART by their friends than younger women. Most agreed that the media reporting on the success of ART for women in midlife was misleading and failed to realistic depict experiences.

Upon reflection, the women felt they knew the risks and benefits of ART; they had made an informed choice, and were satisfied with their decision. They were clear about their decision to use ART, which had not been a hard decision. Women aged 40 years, and older did not agree that their decision to delay childbearing was wise. Most found ART challenging, and as difficult as they had anticipated, yet worthwhile, regardless of the

outcome. They were informed of their ART choices and felt supported but not pressured. More women aged 40 and older would hypothetically not make that decision again to delay childbearing compared to younger women.

Most found the clinic to be sympathetic towards them, and those who had favourable outcomes were more likely to say they had adequate emotional support. As their clinic offered them emotional and psychological support, they did not feel out of control. The procedures of treatment, drugs and the risks of ART were adequately explained. They did not seem influenced by their clinicians to continue ART and had developed awareness that ART was no guarantee of a baby.

Many women found social situations involving children difficult despite being emotionally supported by their family. Women who were childless found it difficult to be with friends who had children, particularly at family gatherings as they felt left out and compared themselves to others with children. Some women felt their friends and relatives with children were leaving them behind.

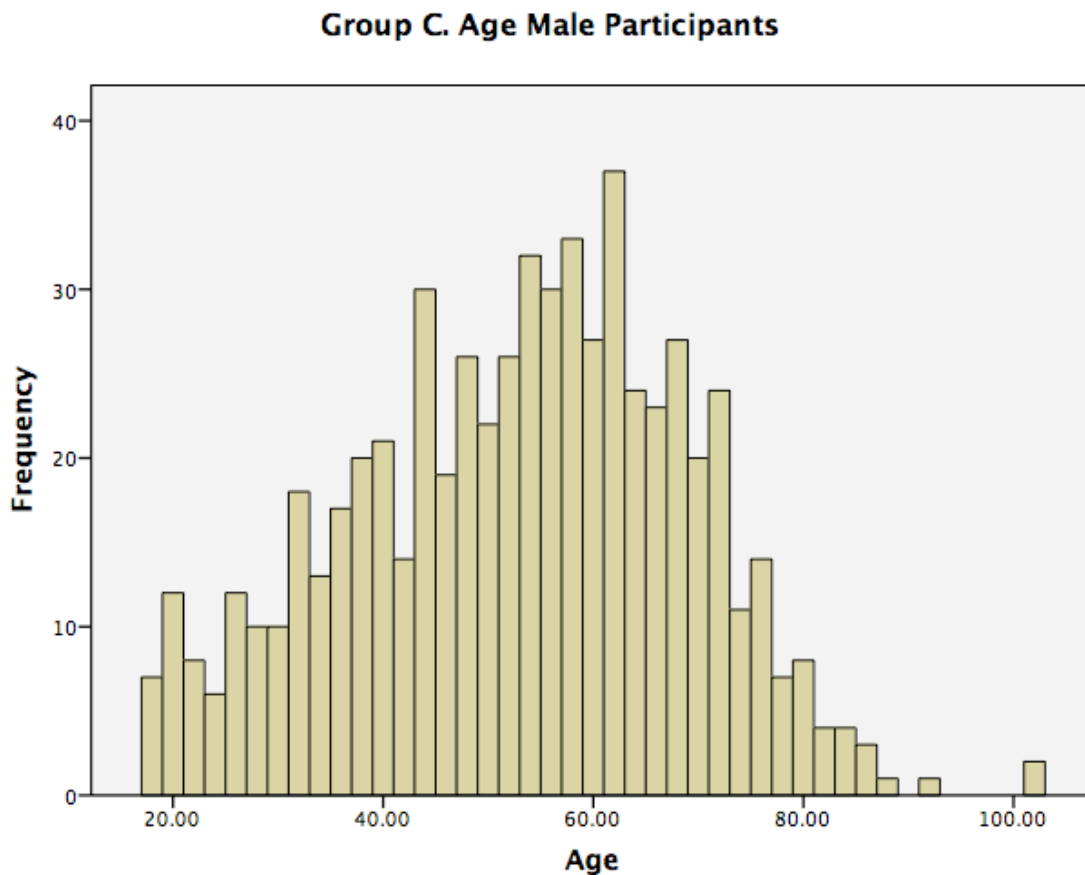
Women who had favourable outcomes did not agree that treatment costs limited the number of treatment cycles. All women, whether they had successfully conceived, decided that they tried ART so they would not regret that they had not tried all their options. As expected, particularly when analysing the data into age groupings, issues with small sample size arose. A larger sample size would be beneficial for more in-depth statistical significance.



## Chapter 7: Group C - Community Survey

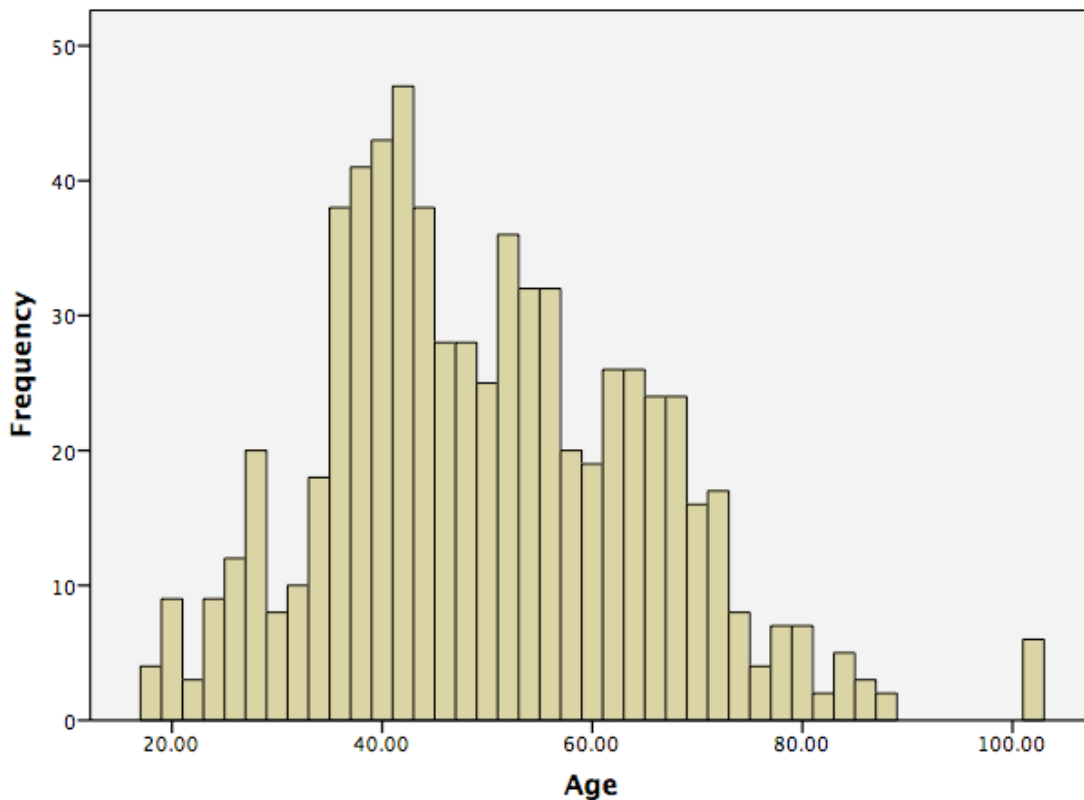
This phone survey was undertaken on behalf of the researcher under strict guidelines for this form of research, as discussed in detail in Chapter 5. The PRI allowed the researcher five questions which are outlined in Chapter 5.5.2, and the effects of gender and age demographics were analysed.

The respondents of Group C with an age range of 18 to 82 years numbered 1243. 50.1% of respondents were male. The mean age of the male participants was 52.35 (SD=16.00) as shown in Figure 7.1. and the mean age of the female participants was 49.57 (SD=15.31) as shown in Figure 7.2. The response rate was 37.1%, cooperation rate was 38.2%, contact rate was 97.8% and the refusal rate was 55.8%.



**Figure 7-1 Group C: Male Participant Ages**

### Group C. Age Female Participants



**Figure 7-2 Group C: Female Participant Ages**

Almost 52% had up to 12 years of education, 47.7% had more than 12 years, and 0.6% did not respond. Data were initially analysed by total responses then for some questions, responses were broken down into gender and age groups. As for Group B the age groups chosen were: 35–39 years and 40 years of age and older.

The five questions each had six analyses undertaken:

- a) All participants of all ages,
- b) Participants aged 35–39 years compared to participants aged 40 years and older,
- c) Men compared to women,
- d) Men aged 35 years or older compared to women aged 35 years or older.
- e) Women aged 35–39 years compared to women aged 40 years or older, and
- f) Men aged 35–39 years compared to men aged 40 years or older.

## 7.1 Main Reason for Delaying Childbearing

The first question inquired about primary reason for women delaying childbearing. The most common reasons are; career aspirations, furthering education, financial reasons, relationship partnering and health.

### 7.1.1 Main reason for delaying childbearing – all ages.

As shown in Table 7.1, the most frequent response was that career or work were the primary reason for women having children later in life. Participants selected financial reasons as the next most common response. The option of lack of a partner was selected by only a small number of respondents, where it rated as a minor response along with the options of health issues and education.

**Table 7-1** Group C: Main Reason for Women Delaying Childbearing

Main reason for women delaying childbearing	Response
Career or Work	589 (53.6)
Financial	440 (40.1)
Lack of partner	46 (4.2)
Education	14 (1.3)
Health	9 (0.8)
Total	1098 (100.0)

*Note.* Number (%)

### 7.1.2 Main reason for delaying childbearing—men and women aged 35–39 years compared to 40 years and older.

Table 7.2 shows the beliefs about the main reason women delay childbearing. Chi-square analysis for trend between reasons for delaying childbearing and the two age groupings

was significant,  $\chi^2(1, N = 994) = 12.704, p = .004$ . Career or work was the most common response for both genders aged 35–39 years and 40 years or older. Participants aged 40 years or older believed that career or work were more influential than did participants aged 35–39 years.

**Table 7-2** Group C: Main Reason for Women Delaying Childbearing Responses between Men and Women aged 35–39 years and 40 years and older

Age	Career or work	Financial	Lack of partner	Education	Health	Total
35–39 years	58 (48.4)	39 (32.5)	19 (15.8)	1 (0.8)	3 (2.5)	120 (100.0)
40 or older	449 (51.4)	356 (40.7)	59 (6.7)	6 (0.7)	4 (0.5)	874 (100.0)
Total	507 (51.0)	395 (39.7)	78 (7.9)	7 (0.7)	7 (0.7)	994 (100.0)

Note. Number (%)

### 7.1.3 Main reason for delaying childbearing—men compared to women all ages.

Views on the main reasons for women to delay childbearing between men and women of all ages are shown in Table 7.3. Chi-square analysis between the reasons for delaying childbearing and gender was significant,  $\chi^2(4, N = 1098) = 11.028, p = .026$ . Around half of men and women selected career or work as the main reason. More men selected career or work than women, and more women than men selected a lack of partner.

**Table 7-3** Group C: Main Reason for Women Delaying Childbearing by Gender for all ages

Gender	Career or work	Financial	Lack of partner	Education	Health	Total
Men	299 (55.8)	212 (39.6)	12 (2.2)	8 (1.5)	5 (0.9)	536 (100.0)
Women	290 (51.6)	228 (40.6)	34 (6.0)	6 (1.1)	4 (0.7)	562 (100.0)
Total	589 (53.6)	440 (40.1)	46 (4.2)	14 (1.3)	9 (0.8)	1098 (100.0)

Note. Number (%)

### 7.1.4 Main reason for delaying childbearing—men aged 35 years and older compared to women aged 35 years and older.

Table 7.4 shows beliefs about the main reason for women to delay childbearing for both genders in the 35 years or older age group. Chi-square analysis between the reasons for delayed childbearing and the two age groups was significant,  $\chi^2(4, N = 1016) = 10.111, p = .038$ . More men than women selected career or work, and more women than men selected lack of a partner.

**Table 7-4** Group C: Main Reason for Women Delaying Childbearing between Men and Women Aged 35 years and Older

Gender	Career or work	Financial	Lack of partner	Education	Health	Total
Men	252	212	12	8	5	489
35 years and older	(51.5)	(43.4)	(2.5)	(1.6)	(1.0)	(100.0)
Women	255	228	34	6	4	527
35 years and older	(48.4)	(43.3)	(6.4)	(1.2)	(0.7)	(100.0)
Total	507	440	46	14	9	1016
	(49.9)	(43.3)	(4.5)	(1.4)	(0.9)	(100.0)

*Note.* Number (%)

### 7.1.5 Main reason for delaying childbearing— women aged 35–39 years compared to women aged 40 years and older.

A comparison between women aged 35–39 years and those aged 40 years or older about the main reason for delaying childbearing is shown in Table 7.5. Chi-square analysis for trend between the reasons and the two age groups was significant,  $\chi^2(1, N = 539) = 7.016, p = .008$ . More women aged 40 years and older selected career or work than younger women.

**Table 7-5** Group C: Reason for Women Delaying Childbearing between Women aged 35–39 years and 40 years and older

Age	Career or work	Financial	Lack of partner	Education	Health	Total
Women Aged 35–39 years	37 (44.1)	27 (32.1)	18 (21.4)	0	2 (2.4)	84 (100.0)
Women aged 40 or older	218 (47.9)	183 (40.3)	50 (11.0)	2 (0.4)	2 (0.4)	455 (100.0)
Total	255 (47.3)	210 (39.0)	68 (12.6)	2 (0.4)	4 (0.7)	539 (100.0)

*Note.* Number (%)

#### 7.1.6 Main reason for delaying childbearing– men aged 35–39 years compared to men aged 40 years and older.

Table 7.6 shows a comparison between men ages 35–39 years and men aged 40 years or older on the main reason why women delay childbearing. Over half the men in both age groups selected career or work as the main reason. Chi-square analysis for trend between men’s views gave and the two age groups was not significant,  $\chi^2(1, N = 455) = 0.188, p = .664$ .

**Table 7-6** Group C: Reason for Women Delaying Childbearing between Men aged 35–39 years and 40 years and older

Age	Career or work	Financial	Lack of partner	Education	Health	Total
Men aged 35–39 years	21 (58.3)	12 (33.3)	1 (2.8)	1 (2.8)	1 (2.8)	36 (100.0)
Men aged 40 years or older	231 (55.1)	173 (41.3)	9 (2.1)	4 (1.0)	2 (0.5)	419 (100.0)
Total	252 (55.4)	185 (40.6)	10 (2.2)	5 (1.1)	3 (0.7)	455 (100.0)

*Note.* Number (%)

## 7.2 Age of Fertility Decline

This question relates to community knowledge on the age range of women’s fertility.

### 7.2.1 Age of fertility decline –all participants.

Table 7.7 shows the responses on fertility decline for the age ranges: 34 years or younger, 35–39 years, and 40 years of age or older. Respondents chose the age range of 35–39 years followed by 40–44 years as the most likely age.

**Table 7-7** Group C: Age of Women’s Fertility Decline all Ages

Age range of fertility decline	Response
34 years or younger	299 (25.3)
35–39 years	543 (45.9)
40 years or older	340 (28.8)
Total	1182 (100.0)

*Note.* Number (%)

### 7.2.2 Age of fertility decline—participants aged 35–39 years and older compared to participants aged 40 years and older.

Table 7.8 shows differences between perceptions of the age of fertility decline between participants aged 35–39 years and those 40 years or more. Around half of the participants in both age groups selected the age of decline as 35–39 years. Chi-square analysis between age of fertility decline and the two age groups was significant,  $\chi^2(2, N = 1061) = 12.087, p = .002$ . More community participants aged 35–39 years of age selected the age of 35–39 years as the age of fertility decline compared to the younger group.

**Table 7-8** Group C: Age of Women’s Fertility Decline between Age Groups 35–39 years and 40 years and older

Age	34 years or younger	35–39 years	40 years or older	Total
35–39 years	32 (23.7)	80 (59.3)	23 (17.0)	135 (100.0)
40 years or older	232 (25.0)	417 (45.0)	227 (30.0)	926 (100.0)
Total	264 (24.9)	497 (46.8)	300 (28.3)	1061 (100.0)

*Note.* Number (%)

### 7.2.3 Age of fertility decline—men compared to women for all ages.

A gender comparison on the age of women’s fertility decline is presented in Table 7.9. Chi-square analysis between age of fertility decline and gender was significant,  $\chi^2(2, N = 1181) = 24.633, p = .000$ . Significantly more women believed that fertility decline started between 35–39 years than men, Whereas more men believed that fertility declined for women in their 40s.



**Table 7-9** Group C: Age of Women's Fertility Decline by Gender for all Ages

Gender	34 years or younger	35–39 years	40 years or older	Total
Men	129 (22.3)	244 (42.3)	204 (35.4)	577 (100.0)
Women	170 (28.1)	299 (49.5)	135 (22.4)	604 (100.0)
Total	299 (25.3)	543 (46.0)	339 (28.7)	1181 (100.0)

*Note.* Number (%)

#### 7.2.4 Age of fertility decline—men aged 35 years and older compared to women aged 35 years and older.

Table 7.10 shows a gender comparison between participants aged 35 years or older on the age of fertility decline. Chi-square analysis between age of fertility decline and gender was significant,  $\chi^2(2, N = 1061) = 31.908, p = .000$ . Significantly more women in this age range believed that a woman's fertility started declining between the ages of 35–39 years than men, and over a third of men of this age believed that fertility declined when women were aged in their 40s.

**Table 7-10** Group C: Age of Women's Fertility Decline by Gender between Men aged 35 years and older and Women aged 35 years and older

Gender	34 years or younger	35–39 years	40 years or older	Total
Men	109 (22.5)	197 (40.7)	178 (36.8)	484 (100.0)
Women	155 (26.8)	300 (52.0)	122 (21.2)	577 (100.0)
Total	264 (24.9)	497 (46.8)	300 (28.4)	1061 (100.0)

*Note.* Number (%)

### 7.2.5 Age of fertility decline – women aged 35–39 years compared to women aged 40 years and older.

Table 7.11 shows the age group differences in women’s perceptions of the age of fertility decline. Chi-square analysis between age of fertility decline and the two age groups was significant,  $\chi^2 (2, N = 577) = 6.832 p = .032$ . Within the female community more participants aged 35–39 years believed women’s fertility started to decline between the ages of 35 to 39 years than those aged 40 years or older. More women aged 40 years or older had a stronger belief that fertility declined at an older age than the younger cohort.

**Table 7-11** Group C: Age of Women’s Fertility Decline Responses Between Women aged 35–39 years and Women Aged 40 years and older

Age	34 years or younger	35–39 years	40 years or older	Total
Women	24	55	10	89
35–39 years	(27.0)	(61.8)	(11.2)	(100.0)
Women	131	245	112	488
40 or older	(26.8)	(50.2)	(23.0)	(100.0)
Total	155	300	122	577
	(26.9)	(52.0)	(21.1)	(100.0)

*Note.* Number (%)

### 7.2.6 Age of fertility decline- men aged 35–39 years compared to men aged 40 years or older.

Age group difference in men’s perceptions of the age of women’s fertility decline is presented in Table 7.12. Chi-square analysis between age of fertility decline and the two age groups for males was significant,  $\chi^2 (2, N = 501) = 12.687, p = .002$ . More men aged 35–39 years than aged 40 years or older supported fertility decline from 35–39 years.

**Table 7-12** Group C: Age of Women's Fertility Decline between Men aged 35–39 years and Men Aged 40 years and older

Age	34 years or younger	35–39 years	40 years or older	Total
Men	2	25	13	40
35–39 years	(5.0)	(62.5)	(32.5)	(100.0)
Men	101	172	188	461
40 or older	(21.9)	(37.3)	(40.8)	(100.0)
Total	103	197	201	501
	(20.6)	(39.3)	(40.1)	(100.0)

*Note.* Number (%)

### 7.3 Likelihood of a pregnancy

This question explores community beliefs of the chance of a conception for women aged 35 years or older using ART.

#### 7.3.1 Likelihood of a pregnancy – participants all ages.

Table 7.13 shows the belief of the community of the chance of a woman aged 35 years and older to get pregnant after ART. Half of the respondents believed women aged 35 years or older were likely to get pregnant after ART, and one third were unsure.

**Table 7-13** Survey C: Beliefs on Likelihood of a Pregnancy Response

Likelihood of a pregnancy	Response
Not likely	201 (17.5)
Neither not likely or likely	373 (32.5)
Likely	574 (50.0)
Total	1148 (100.0)

*Note.* Number (%)

### 7.3.2 Likelihood of a pregnancy—participants aged 35–39 years and older compared to participants aged 40 years or older.

Table 7.14 shows a comparison between participants aged 35–39 years and 40 years or older on the chance of a pregnancy for women aged 35 years or older after ART. Around half of participants believed a pregnancy was likely. Chi-square analysis between age of fertility decline and the two age groups was not significant,  $\chi^2(2, N = 1034) = 3.972, p = .137$ .

**Table 7-14** Group C: Chance of a Pregnancy responses between Age Groups 35–39 years and 40 years and older

Age	Pregnancy not likely	Pregnancy neither not likely or likely	Pregnancy likely	Total
35–39 years	17 (12.7)	45 (33.6)	72 (53.7)	134 (100.0)
40 or older	177 (19.7)	295 (32.7)	428 (47.6)	900 (100.0)
Total	194 (18.7)	340 (32.9)	500 (48.4)	1034 (100.0)

*Note.* Number (%)

### 7.3.3 Likelihood of a pregnancy—men compared to women for all ages.

Table 7.15 shows a comparison between men and women of all ages on the chance of a pregnancy for women aged 35 years or older after ART. Chi-square analysis between beliefs about pregnancy chances and gender was not significant,  $\chi^2(2, N = 1148) = 0.337, p = .845$ .

**Table 7-15** Group C: Likelihood of a Pregnancy by Gender Response all Ages

Gender	Pregnancy not likely	Pregnancy neither not likely or likely	Pregnancy likely	Total
Men	101	178	280	559
all ages	(18.1)	(31.8)	(50.1)	(100.0)
Women	100	195	294	589
all ages	(17.0)	(33.1)	(49.9)	(100.0)
Total	201	373	574	1148
	(17.5)	(32.5)	(50.0)	(100.0)

*Note.* Number (%)

#### 7.3.4 Likelihood of a pregnancy—men aged 35 years or older compared to women aged 35 years or older.

Table 7.16 shows a gender comparison for those aged 35 years or older on the chance of a pregnancy for women aged 35 years or older after ART. Chi-square analysis between age of fertility decline and gender was not significant,  $\chi^2(2, N = 1059) = 0.666, p = .716$ .

**Table 7-16** Group C: Chance of a Pregnancy between Men aged 35 years or older and Women aged 35 years or older

Gender	Pregnancy not likely	Pregnancy neither not likely or likely	Pregnancy likely	Total
Men	85	145	240	470
35 years or older	(18.1)	(30.9)	(51.0)	(100.0)
Women 35 years or older	100	195	294	589
	(17.0)	(33.1)	(49.9)	(100.0)
Total	201	373	574	1059
	(17.5)	(32.5)	(50.0)	(100.0)

*Note.* Number (%)

### 7.3.5 Likelihood of a pregnancy– women aged 35–39 years compared to women aged 40 years or older.

A comparison between women aged 35–39 years and those aged 40 years or older on the chance of a pregnancy after ART is shown in Table 7.17. Chi-square analysis between belief in a pregnancy and the age groups was undertaken on the responses and was not significant,  $\chi^2 (2, N = 564) = 3.312, p=.190$ .

**Table 7-17** Group C: Likelihood of a Pregnancy Women aged 35–39years and 40 years or older

Age	Pregnancy not likely	Pregnancy neither not likely or likely	Pregnancy likely	Total
Women 35–39 years	11 (12.4)	34 (38.2)	44 (49.4)	89 (100.0)
Women 40 or older	98 (20.6)	161 (33.9)	216 (45.5)	475 (100.0)
Total	109 (19.3)	195 (34.6)	260 (46.1)	564 (100.0)

*Note.* Number (%)

### 7.3.6 Likelihood of a pregnancy - men aged 35–39 years compared to men aged 40 years or older.

Table 7.18 shows age group differences in men’s perceptions of the chance of a woman aged 35 years or older getting pregnant after ART. Chi-square analysis between age of pregnancy chance and the two age groups for males was not significant,  $\chi^2 (2, N = 470) = 2.497, p =.286$ .

**Table 7-18** Group C: Likelihood of a Pregnancy between Men aged 35–39 years and Men Aged 40 years or older

Age	Pregnancy not likely	Pregnancy neither not likely or likely	Pregnancy likely	Total
Men 35–39 years	6 (13.3)	11 (24.5)	28 (62.2)	45 (100.0)
Men 40 or older	79 (18.5)	134 (31.5)	212 (50.0)	425 (100.0)
Total	85 (18.1)	145 (30.9)	240 (51.0)	470 (100.0)

*Note.* Number (%)

## 7.4 Likelihood of a healthy baby

Chances of having a live birth after an ART-conceived pregnancy is lower for midlife intending mothers, and the lower success rate can be attributed to physiological factors, as discussed in Chapter 4. Most participants (66.1%) believed that women aged over 35 years who conceived after ART would go on to have a healthy baby.

### 7.4.1 Likelihood of a healthy baby for all participants.

Table 7.19 shows the age group differences in participant’s beliefs of the chance of a woman aged 35 years having a healthy baby after ART. Most participants believed that women of this age who conceived via ART would give birth to a health baby.

**Table 7-19** Group C: Likelihood of a Healthy Baby

Likelihood of a baby	Response
Not Likely	96 (8.3)
Neither likely or not likely	296 (25.6)
Likely	764 (66.1)
Total	1156 (100.0)

*Note.* Number (%)

#### 7.4.2 Likelihood of a healthy baby- participants aged 35–39 years and older compared to participants aged 40 years or older.

Table 7.20 shows the differences between participants aged 35–39 years and 40 years or older on the likelihood of a birth after ART. Chi-square analysis between likelihood of a birth and the two age groups was not significant,  $\chi^2(2, N = 1043) = 1.809, p = .405$ .

**Table 7-20** Group C: Likelihood of a Healthy Baby between Men aged 35 years or older and Women aged 35 years or older

Age	Healthy baby not likely	Healthy baby neither not likely or likely	Healthy baby likely	Total
35–39 years	14 (10.5)	39 (29.3)	80 (60.2)	133 (100.0)
40 years or older	76 (8.3)	234 (25.7)	600 (66.0)	910 (100.0)
Total	90 (8.6)	273 (26.2)	680 (65.2)	1043 (100.0)

*Note.* Number (%)



### 7.4.3 Likelihood of a healthy baby- men compared to women for all ages.

Table 7.21 shows the differences between men and women of all ages on the likelihood of a healthy baby after ART. Chi-square analysis between belief in a birth after ART and gender was not significant,  $\chi^2 (2, N = 1156) = .934, p = .630$ .

**Table 7-21** Group C: Likelihood of a Baby by Gender

Gender	Live birth not likely	Live birth neither not likely or likely	Live birth likely	Total
Male	44 (7.7)	151 (26.7)	371 (65.6)	566 (100.0)
Female	52 (8.8)	145 (24.5)	393 (66.7)	590 (100.0)
Total	96 (8.3)	296 (25.6)	764 (66.1)	1156 (100.0)

*Note.* Number (%)

#### 7.4.4 Likelihood of a health baby- men aged 35 years and older compared to women aged 35 years and older.

Table 7.22 shows the differences between men and women all aged 35 years or older on the likelihood of a healthy baby after ART. Chi-square analysis between chance of a healthy baby and gender was not significant,  $\chi^2(2, N = 1043) = 3.959, p = .138$ .

**Table 7-22** Group C: Likelihood of a Healthy Baby by Gender between Men aged 35 years and older and Women aged 35 years and older

Gender	Healthy baby not likely	Healthy baby neither not likely or likely	Healthy baby likely	Total
Men	34	119	325	478
35 years or older	(7.1)	(24.9)	(68.0)	(100.0)
Women 35 years or older	56	154	355	565
	(9.9)	(27.3)	(62.8)	(100.0)
Total	90	273	680	1043
	(8.6)	(26.2)	(65.2)	(100.0)

*Note.* Number (%)

#### 7.4.5 Likelihood of a healthy baby – women aged 35–39 years compared to women aged 40 years and older.

Differences between women aged 35 –39 years and those aged 40 years or older on the likelihood of a healthy baby after ART are shown in Table 7.23. Chi-square analysis between belief in a birth and age group was not significant,  $\chi^2(2, N = 565) = 1.016, p = .602$ .

**Table 7-23** Group C: Likelihood of a Healthy Baby between Women aged 35–39years and Women 40 years or older

Age	Healthy baby not likely	Healthy baby neither not likely or likely	Healthy baby likely	Total
Women 35–39 years	9 (10.1)	28 (31.5)	52 (58.4)	89 (100.0)
Women 40 or older	47 (9.9)	126 (26.5)	303 (63.6)	476 (100.0)
Total	56 (9.9)	154 (27.3)	355 (62.8)	565 (100.0)

*Note.* Number (%)

#### 7.4.6 Likelihood of a healthy baby - men aged 35–39 years compared to men aged 40 years and older.

Table 7.24 shows age group comparisons between men aged 35–39 years and those aged 40 years or older about a birth after ART. Chi-square analysis between likelihood and two age groups was not significant,  $\chi^2$  (2,  $N = 478$ ) = 1.366,  $p = .505$ .

**Table 7-24** Group C: Likelihood of a Pregnancy between Men aged 35–39 years and Men Aged 40 years and older

Age	Healthy baby not likely	Healthy baby neither not likely or likely	Healthy baby likely	Total
Men 35–39 years	5 (11.4)	11 (25.0)	28 (63.6)	44 (100.0)
Men 40 or older	29 (6.7)	108 (24.9)	297 (68.4)	434 (100.0)
Total	34 (7.1)	119 (24.9)	325 (68.0)	478 (100.0)

*Note.* Number (%)

## 7.5 Media portrayal

As discussed in Chapter 4.8, media plays an important role in demystifying medical issues and a pivotal role in shaping of public opinion on medical issues and health risks. This question explores whether community members believe that media portrays ART as successful for older women.

### 7.5.1 Media Influence– Participants all Ages.

Table 7.25 shows most community members (73.5%) agreed that the media portrays ART as a successful way for older women to get pregnant.

**Table 7-25** Group C: Media Portrayal of ART Response-Participants all Ages

Media positively portrays IVF as successful for older women	Response
Yes	904 (73.5)
No	212 (17.2)
Unsure	114 (9.3)
Total	1230 (100.0)

*Note.* Number (%)

### 7.5.2 Media Influence - participants aged 35–39 years and older compared to participants aged 40 years and older.

Table 7.26 shows a comparison for those aged 35-39 years and 40 and older on their perceptions of media portrayal of ART. Chi-square analysis between media influence and the two groups was not significant,  $\chi^2(2, N = 1104) = 2.296, p = .317$ .

**Table 7-26** Group C: Media Portrayal of ART Participants aged 35–39 years and Older Compared to age 40 years or Older

Age	Media portrays ART as successful	Media does not portray ART as successful	Unsure if Media portrays ART as successful	Total
35–39 years	110 (79.8)	18 (13.0)	10 (7.2)	138 (100.0)
40 years or older	712 (73.7)	161 (16.7)	93 (9.6)	966 (100.0)
Total	822 (74.5)	179 (16.2)	103 (9.3)	1104 (100.0)

*Note.* Number (%)

### 7.5.3 Media influence- men compared to women for all ages.

Table 7.27 shows a gender comparison for all ages. Chi-square analysis between media portrayal and gender was close to significance,  $\chi^2(2, N = 1230) = 5.907, p = .052$ . More women believed that the media portrays ART as successful.

**Table 7-27** Group C: Beliefs on the Media Portrayal of ART by Gender

Gender	Media portrays ART as successful	Media not portrays ART as successful	Unsure if Media portrays ART as successful	Total
Men	438 (71.4)	106 (17.3)	69 (11.3)	613 (100.0)
Women	466 (75.5)	106 (17.2)	45 (7.3)	617 (100.0)
Total	904 (73.5)	212 (17.2)	114 (9.3)	1230 (100.0)

*Note.* Number (%)

#### 7.5.4 Media influence-men aged 35 years or older compared to women aged 35 years or older.

Table 7.28 shows a comparison between men and women aged 35 years or older. Chi-square analysis between media portrayal and these groups was close to significance,  $\chi^2(2, N = 1104) = 5.854, p = .054$ .

Table 7-28 Group C: Beliefs on the Media Portrayal of ART by Gender Men and Women aged 35 years or Older

Gender	Media portrays ART as successful	Media not portrays ART as successful	Unsure if Media portrays ART as successful	Total
Men	371 (71.6)	88 (17.0)	59 (11.4)	518 (100.0)
Women	451 (77.0)	91 (15.5)	44 (7.5)	586 (100.0)
Total	822 (74.5)	179 (16.2)	103 (9.3)	1104 (100.0)

*Note.* Number (%)

#### 7.5.5 Media Influence- women aged 35–39 years compared to women aged 40 years or older.

A comparison between women aged 35–39 years of age and those aged 40 years or older is shown in Table 7.29. Chi-square analysis between media portrayal and the two groups was not significant,  $\chi^2(2, N = 586) = 4.186, p = .123$ .

**Table 7-29 Group C:** Media Portrayal of ART Women aged 35–39 years Compared to Women aged 40 years or older

Age	Media portrays ART as successful	Media not portrays ART as successful	Unsure if Media portrays ART as successful	Total
35–39 years of age	77 (84.6)	11 (12.1)	3 (3.3)	91 (100.0)
40 years or older	374 (75.5)	80 (16.2)	41 (8.3)	495 (100.0)
Total	451 (77.0)	91 (15.5)	44 (7.5)	586 (100.0)

### 7.5.6 Media Influence- men aged 35–39 years compared to men aged 40 years and older.

Table 7.30 shows a comparison between men aged 35–39 years of age and those aged 40 years or older. Chi-square analysis between media portrayal across the groups was not significant,  $\chi^2(2, N = 586) = 4.186, p = .123$ .

**Table 7-30 Group C:** Media Portrayal of ART Men aged 35–39 years compared to Men aged 40 years or Older

Age	Media portrays ART as successful	Media does not portray ART as successful	Unsure if Media portrays ART as successful	Total
35–39 years of age	33 (70.2)	7 (14.9)	7 (14.9)	47 (100.0)
40 years or older	338 (71.8)	81 (17.2)	52 (11.0)	471 (100.0)
Total	371 (71.6)	88 (17.0)	59 (11.4)	518 (100.0)

*Note.* Number (%)

## 7.6 Summary

Community members (N=1243) provided valuable data regarding fertility perceptions and beliefs. Career or work was perceived as the primary reason for women delaying having children for all age groups and gender. Financial security was the second most common response, and lack of a partner not a frequent response.

The age ranges 35–39 years was the most commonly selected response as the age of fertility decline; this is consistent with the medical literature. However, around a quarter of the community decided the age of 40 years and older as the age at which fertility declines. Those aged 35–39 years were more likely to choose the ages of 35–39 years as the age of decline while the older respondents believed fertility declined for women over the age of 40 years. Women, particularly those over 35 years, were more likely to correctly select the age of 35 years as when fertility significantly declines.

Almost half of the respondents believed women aged 35 years or older were likely to get pregnant and deliver a healthy baby after ART. Men (all ages) and community members aged 40 years or older were more confident of a healthy baby. There was no significant difference between the beliefs across age groups and genders. In general, community members had faith in the success of ART for women aged 35 years or older.

A large proportion of the surveyed community believed that media portrays ART as a successful way for older women to become pregnant, with some strongly holding this view. Data also showed that some community members are unsure about fertility and ART. In particular, one-quarter to one-third of respondents were confused about the likelihood of pregnancy or live birth for women aged 35 years and older. Chapter 8 presents results of a comparison of data for these five questions for Groups B and C.



## Chapter 8: Comparison between Groups B and C

This chapter presents the comparison between women in Groups B and C. Survey responses from participants in Group B (68 women in a support group who had used ART) and Group C (1243 men and women in the general community) were compared. Five questions were asked of participants in these two surveys as discussed in Chapter 5. Responses were further divided into two age groups: 35–39 years and 40 years of age or older, and comparisons made between women in each group.

### 8.1 Main Reason for Delaying Childbearing

The most common reasons for women delaying childbearing, as discussed in Chapter 3.4, were compared cross the two groups of participants.

#### 8.1.1 Main Reason for Delaying Childbearing- Groups B and C all ages.

Table 8.1 shows the main reason women delay childbearing for Groups B and C. Chi-square analysis for trend between reasons for delay and the two groups was significant,  $\chi^2(1, N = 1161) = 172.783, p = .001$ . More support group members believed lack of a partner was the major reason while more community members believed career or work was the main reason for women delaying childbearing.

**Table 8-1 Groups B and C: Main Reason for Women Delaying Childbearing all Ages**

Group	Career or work	Financial	Lack of partner	Education	Health	Total
Group B	15 (23.8)	8 (12.7)	39 (61.9)	0	1 (1.6)	63 (100.0)
Group C	589 (53.6)	440 (40.1)	46 (4.2)	14 (1.3)	9 (0.8)	1098 (100.0)
Total	604 (52.0)	448 (38.6)	85 (7.3)	14 (1.2)	10 (0.9)	1161 (100.0)

*Note.* Number (%)

### 8.1.2 Main Reason for Delaying Childbearing- Groups B and C aged 35 years or older.

Beliefs about the main reason for women to delay childbearing between men and women in Groups B and C aged 35 years or older is shown in Table 8.2. Chi-square analysis for trend between beliefs across the two groups was significant,  $\chi^2(1, N = 1161) = 656.689, p = .000$ . Most in the support group aged 35 years or older believed lack of a partner, while half of the community in this age group believed career or work was the main reason for women delaying childbearing.

**Table 8-2 Groups B and Group C: Main Reason for Women Delaying Childbearing aged 35 years or Older**

Group	Career or work	Finance	Lack of partner	Education	Health	Total
Group B	14	7	397	0	1	59
All aged 35 years or older	(23.7)	(11.9)	(62.7)		(1.7)	(100.0)
Group C	493	388	41	7	6	935
All aged 35 years or older	(52.7)	(41.5)	(4.5)	(0.7)	(0.6)	(100.0)
Total	507	395	78	7	7	994
	(51.1)	(39.7)	(7.8)	(0.7)	(0.7)	(100.0)

*Note.* Number (%)

### 8.1.3 Main reason for delaying childbearing- Groups B and C Women aged 35–39 years.

Table 8.3 shows the beliefs about the main reason for women to delay childbearing for women in Groups B and C aged 35–39 years of age. Chi-square analysis for trend between reasons across the two groups was significant,  $\chi^2(1, N = 84) = 15.142, p = .000$ . Half of women in the support group aged 35–39 years of age believed lack of a partner and half of females in the community of this age believed career or work was the main reason for women delaying childbearing.

**Table 8-3 Groups B and C: Women aged 35–39 years of age on Reason for Women Delaying Childbearing**

Group	Career or work	Finance	Lack of partner	Education	Health	Total
Group B	6	4	13	0	1	24
Women aged 35– 39 years	(25.0)	(16.6)	(54.2)		(4.2)	(100.0)
Group C	31	23	5	0	1	60
Women aged 35–39 years	(51.7)	(38.3)	(8.3)		(1.7)	(100.0)
Total	37	27	18	0	2	84
	(44.1)	(32.1)	(21.4)		(2.4)	(100.0)

*Note.* Number (%)

#### **8.1.4 Main reason for delaying childbearing- Groups B and C women aged 40 years or older**

Table 8.4 shows the main reason for women to delay childbearing between women in Groups B and C in the 40 or older category. Chi-square analysis for trend between reasons across the two groups was significant,  $\chi^2(1, N = 455) = 82.384, p=.000$ . Most women in the support group aged 40 years or older believed lack of a partner and half the participants in the community in this age group believed career or work was the main reason for women delaying childbearing.

**Table 8-4 Groups B and C: Women aged 40 years or older on Reason for Women Delaying Childbearing**

Group	Career or work	Financial	Lack of partner	Education	Health	Total
Group B	8	3	24	0	0	35
Women aged 40 and older	(22.8)	(8.6)	(68.6)			(100.0)
Group C	210	180	26	2	2	420
Women aged 40 and older	(50.0)	(42.8.)	(6.2)	(0.5)	(0.5)	(100.0)
Total	218	183	50	2	2	455
	(47.9)	(40.3)	(11.0)	(0.4)	(0.4)	(100.0)

*Note.* Number (%)

## 8.2 Age of fertility decline

As discussed in Chapter 4.2, female fertility declines with increasing maternal age. Participants were asked about their beliefs about the age when fertility begins to significantly decline for women.

### 8.2.1 Age of fertility decline – Groups B and C all ages.

Table 8.5 shows beliefs on the age of fertility decline in Groups B and C. Chi-square analysis between age of decline and the two groups was significant,  $\chi^2(2, N = 1244) = 16.568, p = .000$ . Over half of participants in both groups believed fertility declined between 35–39 years. A quarter of community members believed that fertility declined at 40 years or older whereas only a small number of Group B held the same belief.

**Table 8-5 Groups B and C: Age of Fertility Decline all Ages**

Group	34 years or younger	35-39 years	40 years or older	Total
Group B	16 (25.8)	42 (67.7)	4 (6.5)	62 (100.0)
Group C	299 (25.3)	543 (45.9)	340 (28.8)	1182 (100.0)
Total	315 (25.3)	585 (47.0)	344 (27.7)	1244 (100.0)

*Note.* Number (%)

### 8.2.2 Age of fertility decline- Groups B and C aged 35 years or older.

Table 8.6 shows beliefs of participants aged 35 years or older on the age of female fertility decline in Groups B and C. Chi-square analysis between age of decline and the two groups was significant,  $\chi^2(2, N = 1061) = 15.558, p = .000$ . Two thirds of the support group compared to less than half of the community believed fertility declined between the 35–39 years. A third of community members believed that fertility declined at 40 years or older compared to a small number of support group members.

**Table 8-6 Groups B and C: Age of Fertility Decline aged 35 years or Older**

Group	34 years or younger	35–39 years	40 years or older	Total
Group B	16	39	4	59
aged 35 years or older	(27.1)	(66.1)	(6.8)	(100.0)
Group C	248	458	296	1002
aged 35 years or older	(24.8)	(45.7)	(29.5)	(100.0)
Total	264	497	300	1061
	(24.9)	(46.8)	(28.3)	(100.0)

*Note.* Number (%)

### 8.2.3 Age of fertility decline –Groups B and C females aged 35–39 years.

Beliefs of female participants in Groups B and C aged 35–39 years on the age of women’s fertility decline is shown in Table 8.7. Chi-square analysis for trend between age of decline and the two groups was not significant,  $\chi^2(1, N = 89) = 3.545, p = .059$ .

**Table 8-7 Groups B and C: Women on Age of Fertility Decline aged 35–39 years**

Group	34 years or younger	35–39 years	40 years or older	Total
Group B	9	15	0	24
Women aged 35–39 years	(37.5)	(62.5)		(100.0)
Group C	15	40	10	65
Women aged 35–39 years	(23.1)	(61.5)	(15.4)	(100.0)
Total	24	55	10	89
	(27.0)	(61.8)	(11.2)	(100.0)

*Note.* Number (%)

#### 8.2.4 Age of fertility decline –Groups B and C females aged 40 years or older.

Table 8.8 shows beliefs of women aged 40 years or older on age of fertility decline in Groups B and C. A chi-square test between the age of decline and the two groups was not significant,  $\chi^2(2, N = 488) = 5.372, p = .068$ .

**Table 8-8 Groups B and C: Women on Age of Fertility Decline aged 40 years and older**

Group	34 years or younger	35–39 years	40 years or older	Total
Group B Women aged 40 years or older	7 (20.0)	24 (68.6)	4 (11.4)	35 (100.0)
Group C Women aged 40 years or older	124 (27.4)	221 (48.8)	108 (23.8)	453 (100.0)
Total	131 (26.8)	245 (50.2)	112 (23.0)	488 (100.0)

*Note.* Number (%)

### 8.3 Likelihood of a pregnancy

Participants were asked about their beliefs in an ART-conceived pregnancy for women aged 35 years or older.

### 8.3.1 Likelihood of a pregnancy- Groups B and C all ages.

Table 8.9 shows the beliefs of Groups B and C on the likelihood of pregnancy after ART. Chi-square analysis between likelihood and the two groups was significant,  $\chi^2(2, N = 1210) = 13.88, p = .000$ . Half of community members compared to a quarter of the support group believed a pregnancy was likely after ART.

**Table 8-9 Groups B and C: Likelihood of a Pregnancy all Ages**

Group	Pregnancy not Likely	Pregnancy neither not Likely or Likely	Pregnancy Likely	Total
Group B	17 (27.4)	29 (46.8)	16 (25.8)	62 (100.0)
Group C	201 (17.5)	373 (32.5)	574 (50.0)	1148 (100.0)
Total	218 (18.1)	402 (33.2)	590 (48.7)	1210 (100.0)

*Note.* Number (%)

### 8.3.2 Likelihood of a pregnancy- Groups B and C aged 35 years or older.

Table 8.10 shows the beliefs of Groups B and C aged 35 years or older on the likelihood of a pregnancy after ART. Chi-square analysis between likelihood across the two groups was significant,  $\chi^2(2, N = 1034) = 13.331, p = .001$ . In this age range, half of the community compared to a quarter of the support group believed a pregnancy was likely after ART.

**Table 8-10 Groups B and C: Likelihood of Pregnancy aged 35 years or older**

Group	Pregnancy not Likely	Pregnancy Neither not Likely or Likely	Pregnancy Likely	Total
Group B	17 (28.8)	27 (45.8)	15 (25.4)	24 (100.0)
All aged 35–39 years				
Group C	177 (18.2)	313 (32.1)	485 (49.7)	65 (100.0)
All aged 35–39 years				
Total	194 (18.8)	340 (32.9)	500 (48.3)	1034 (100.0)

Note. Number (%)

### 8.3.3 Likelihood of a pregnancy- Groups B and C females aged 35–39 years.

Beliefs of women aged 35-39 years in Groups B and C on the likelihood of a pregnancy after ART is shown in Table 8.11. Chi-square analysis between likelihood and the two groups was significant,  $\chi^2 (2, N = 89) = 9.415, p = .009$ . For women in this age group, half of community members compared to a quarter of the support group believed a pregnancy was likely.

**Table 8-11 Group B and C: Likelihood of Pregnancy Women aged 35–39 years**

Group	Pregnancy not likely	Pregnancy neither not likely or likely	Pregnancy likely	Total
Group B	6	12	6	24
Women aged 35–39 years	(25.0)	(50.0)	(25.0)	(100.0)
Group C	5	22	38	65
Women aged 35–39 years	(7.7)	(33.8)	(58.5)	(100.0)
Total	11	34	44	89
	(12.4)	(38.2)	(49.4)	(100.0)

Note. Number (%)

### 8.3.4 Likelihood of a pregnancy- Groups B and C females aged 40 years or older.

Table 8.12 shows the beliefs of females aged 40 years or older in Groups B and C on likelihood of a pregnancy after ART. Chi-square analysis between likelihood and the two groups was significant,  $\chi^2 (2, N = 475) = 6.274, p = .043$ . For women in this older age group, half of the community compared to a quarter of the support group believed a pregnancy was likely.



**Table 8-12 Groups B and C: Likelihood of Pregnancy Women aged 40 years or older**

Group	Pregnancy not likely	Pregnancy neither not likely or likely	Pregnancy likely	Total
Group B	11	15	9	35
Women aged 40 years or older	(31.4)	(42.9)	(25.7)	(100.0)
Group C	87	146	207	440
Women aged 40 years or older	(19.8)	(33.2)	(47.0)	(100.0)
Total	98	161	216	475
	(20.6)	(33.9)	(45.5)	(100.0)

*Note.* Number (%)

#### **8.4 Group C: Likelihood of a Healthy Baby for Women aged 35 years**

Participants were asked about their beliefs for an ART-conceived pregnancy progressing to the birth of a healthy baby for women aged 35 years or older.

##### **8.4.1 Likelihood of a healthy baby – Groups B and C all ages.**

Beliefs of both groups about likelihood of a birth after ART are shown in Table 8.13. Chi-square analysis between likelihood of a birth and the two groups was significant,  $\chi^2(2, N = 1218) = 27.463, p = .000$ . A third of the support group compared to two-thirds of the community group had expectations of a healthy baby.

**Table 8-13 Groups B and C: Likelihood of a Healthy Baby all Ages**

Group	Healthy baby not likely	Healthy baby not likely or likely	Healthy baby likely	Total
Group B	12 (19.3)	29 (46.8)	21 (33.9)	62 (100.0)
Group C	96 (8.3)	296 (25.6)	764 (66.1)	1156 (100.0)
Total	108 (8.9)	325 (26.7)	785 (64.4)	1218 (100.0)

*Note.* Number (%)

#### 8.4.2 Likelihood of a healthy baby – Groups B and C aged 35 years or older.

Table 8.14 shows beliefs of Groups B and C members aged 35 years or older on the likelihood of a healthy baby after ART. Chi-square analysis between likelihood across the two groups was significant,  $\chi^2(2, N = 1043) = 30.326, p = .000$ . A third of the support group compared to two-thirds of the community group of this age had expectations of a healthy baby.

**Table 8-14 Groups B and C: Likelihood of a Healthy Baby aged 35 years or older**

Group	Healthy baby not likely	Healthy baby not likely or likely	Healthy baby likely	Total
Group B aged 35 years or older	11 (18.6)	29 (49.2)	19 (32.2)	59 (100.0)
Group C aged 35 years or older	79 (8.0)	244 (24.8)	661 (67.2)	984 (100.0)
Total	90 (8.6)	273 (26.2)	680 (65.2)	1043 (100.0)

*Note.* Number (%)

### 8.4.3 Likelihood of a healthy baby- Groups B and C women aged 35–39 years.

Table 8.15 shows beliefs of women aged 35-39 years of age in Groups B and C on the likelihood of a healthy baby after ART. Chi-square analysis between likelihood and the two groups was significant,  $\chi^2 (2, N = 89) = 19.227, p = .000$ . One-fifth of the support group women compared to three-quarters of women in the community group in this age group had expectations of a healthy baby after ART.

**Table 8-15 Groups B and C: Likelihood of a Birth Women aged 35 years or older**

Group	Healthy baby not likely	Healthy baby neither likely or likely	Healthy baby likely	Total
Group B	5	14	5	24
Women aged 35–39 years	(20.8)	(58.3)	(20.9)	(100.0)
Group C	4	14	47	65
Women aged 35–39 years	(6.2)	(21.5)	(72.3)	(100.0)
Total	9	28	52	89
	(11.1)	(31.4)	(58.4)	(100.0)

*Note.* Number (%)

### 8.4.4 Likelihood of a healthy baby- Groups B and C women aged 40 years or older.

Table 8.16 shows beliefs of women aged 40 years or older in Groups B and C on the likelihood of a healthy baby after ART. Chi-square analysis between likelihood and the two groups was significant,  $\chi^2 (2, N = 476) = 9.175, p = .010$ . About 40% of the support group women of this age compared to 65% of women in the community aged 40 years or older had expectations of a healthy baby after ART.

**Table 8-16 Groups B and C: Likelihood of a Birth Women aged 40 years or older**

Group	Healthy baby not likely	Healthy baby neither not likely or likely	Healthy baby likely	Total
Group B	6	15	14	35
Women aged 40 years or older	(17.1)	(42.9)	(40.0)	(100.0)
Group C	41	111	289	441
Women aged 40 years or older	(9.3)	(25.2)	(65.5)	(100.0)
Total	47	126	303	476
	(9.9)	(26.5)	(63.6)	(100.0)

*Note.* Number (%)

## 8.5 Media influence

Participants were asked if they believed the media portrayed ART as a successful way for women aged 35 years or older to have a child.

### 8.5.1 Media Influence- Groups B and C all ages.

Table 8.17 shows the beliefs of Groups B and C regarding media portrayal of ART success. Chi-square analysis between media influence and the two groups was not significant,  $\chi^2(2, N = 1291) = 4.182, p = .124$ .

**Table 8-17 Groups B and C: Media Influence all Ages**

Group	Yes	No	Unsure	Total
Group B	52	6	3	61
	(85.3)	(9.8)	(4.9)	(100.0)
Group C	904	212	114	1230
	(73.5)	(17.2)	(9.3)	(100.0)
Total	956	218	117	1291
	(74.1)	(16.8)	(9.1)	(100.0)

*Note.* Number (%)

### 8.5.2 Media Influence- Groups B and C aged 35 years or older.

Table 8.18 shows the beliefs of Groups B and C aged 35 years or older on media portrayal of ART success. Chi-square analysis between media influence and the two groups was significant,  $\chi^2(2, N = 1104) = 7.636, p = .022$ . Support group members of this age have a stronger belief that the media portrays ART as successful.

**Table 8-18 Groups B and C: Media Influence aged 35 years or older**

Group	Yes	No	Unsure	Total
Group B	52	3	3	58
All aged 35 years or older	(89.6)	(5.2)	(5.2)	(100.0)
Group C	770	176	114	1060
All aged 35 years or older	(72.6)	(16.6)	(10.8)	(100.0)
Total	822	179	117	1118
	(73.5)	(16.0)	(10.5)	(100.0)

*Note.* Number (%)

### 8.5.3 Media influence- Groups B and C women aged 35–39 years.

Beliefs of women aged 35–39 years in Groups B and C about media portrayal of success of ART are shown in Table 8.19. Chi-square analysis for trend between media influence and the two groups was not significant,  $\chi^2(1, N = 91) = 1.131, p = .287$ .

**Table 8-19 Groups B and C: Media Influence Women aged 35–39 years**

Group	Yes	No	Unsure	Total
Group B	22	1	1	24
Women aged 35–39 years	(91.6)	(4.2)	(4.2)	(100.0)
Group C	55	10	2	67
Women aged 35–39 years	(82.1)	(14.9)	(3.0)	(100.0)
Total	77	11	3	91
	(84.6)	(12.1)	(3.3)	(100.0)

*Note.* Number (%)

#### 8.5.4 Media Influence- Groups B and C women aged 40 years or older.

Table 8.20 shows beliefs of women aged 40 years or older in Groups B and C on media portrayal of ART success. Chi-square analysis between Surveys B and C on portrayal of ART was not significant,  $\chi^2(2, N = 495) = 3.418, p = .181$ .

**Table 8-20 Groups B and C: Media Influence Women aged 40 years or older**

Group	Yes	No	Unsure	Total
Group B	30	2	2	34
Women 40 years or older	(88.2)	(5.9)	(5.9)	(100.0)
Group C	344	78	39	461
Women 40 years or older	(74.6)	(16.9)	(8.5)	(100.0)
Total	374	80	41	495
	(75.5)	(16.2)	(8.3)	(100.0)

*Note.* Number (%)

## 8.6 Summary

Support group members who had engaged with ART had significantly different responses to the community group across the five key questions. They believed the primary reason for women approaching motherhood at a later age was that a relationship partner was desirable before starting a family. Conversely, community members believed that women's career or work commitments were the primary reasons for delayed motherhood.

The most common response from both the support group and the community was that female fertility starts to decline from the age of 35–39 years. One-quarter of the support group believed fertility started declining from the age of 25 years while a quarter of the

community believed fertility declines from 40 years of age. There was no significant difference between the beliefs of women in both groups in the age groups 35-39 years and 40 and older.

There was a significant difference between beliefs of the two groups for an ART-conceived pregnancy for women aged 35 or older. Only one-quarter of the support group believed women aged 35 years or older were likely to get pregnant compared to half the of the community.

Similarly, there was a significant difference between the two groups on their beliefs of the chance of a healthy baby after ART for women aged 35 or older. The community were more confident of a healthy baby than those in the support group. More of the support group were unsure than the community on likelihood of a baby.

Both groups, and for all ages, were in agreement that media portrays ART as a successful way for older women to conceive. There was a significant difference between those aged 35 –39 years in both groups, with the support group having a stronger belief than the community that media portrays ART as successful. Women who had experienced ART had a more realistic understanding of these matters than the community. Chapter 9 contains qualitative data from the support and focus groups.to expand upon the quantitative findings.

## Chapter 9: Qualitative Results

“I just can’t see life without having children” (TO).

### 9.1 Introduction

Qualitative data were gathered in this study to triangulate findings from the quantitative surveys and to gain a better insight into the perceptions and experiences of women who had used ART. Results are detailed in this chapter.

### 9.2 Participants

Participants were aged 35 years or older when they engaged with ART. Qualitative data were gathered from two groups of women who were undertaking or had recently undertaken ART; Group D involved six women in lengthy face-to-face interviews with a neutral facilitator while Survey B responses arose from open written comments from 23 participants. These 29 women had a mix of ART history and success – some were still undertaking treatment while others had disengaged from ART. Some women who were successful initially had previous of subsequent unsuccessful cycles, enabling a broad experience with ART treatment to be reflected in comments and discussion.

#### 9.2.1 Group D Interviews

All six participants in Group D were either recently or currently using ART. They were asked to tell the story of their ART journey with the outline of the interview script shown in Appendix 1. Each participated in a one-hour interview; five interviews were held in face-to-face sessions in Brisbane and one interview was conducted via telephone as the participant lived in regional Queensland

These face-to-face interviews were audiotaped, transcribed and data were de-identified. The responses were pooled and coded by two independent researchers. The researchers immersed themselves in the data before common themes became evident. Responses were organised into 13 sections and outlined in this chapter.



### **9.2.2 Group D Participant Profiles**

Six participants took part in focus group interviews; their details and codes for analysis are as follows:

- 1) AN is aged 40 years, has a daughter and had undertaken ART for three years. She started ART at the age of 37 and got pregnant on her fifth IVF cycle.
- 2) JA is aged 44 years and is starting her 12th IVF cycle within three years. JA has now chosen to access donor egg and sperm because of her diminished oocyte quality and her partner's poor semen parameters.
- 3) LL is aged 42 years and had her first ART cycle when aged 41.
- 4) SH is aged 41 and is 14 weeks pregnant after ART and has a daughter from ART.
- 5) SJ is aged 37 years and completed her 17th ART cycle. She has now chosen to use donor oocytes rather than autologous oocytes. In total, she has experienced one miscarriage, has a son born in 2006 and had two ectopic pregnancies resulting in the removal of both fallopian tubes.
- 6) TO is aged 38 years. She had several miscarriages, a triplet pregnancy leading to a birth at 24 weeks gestation with the neonatal death of the triplets, and a live birth after seven cycles of ART. She was nine weeks pregnant at the time of the interview. Nine cycles had been undertaken at the date of the interview.

### **9.2.3 Interview Questions Group D**

Participants were asked 12 questions that covered their experiences and expectations of ART as detailed in Chapter 5.7.2. The interviewer asked the participants about: their experience at the infertility clinic; outcomes of their ART treatment; their understanding of women's fertility decline; social reasons why women may postpone childbearing; their belief of the probability for a woman in midlife to have a baby using ART; whether media and marketing framed their expectations of success; decisions to stop treatment and whether they had recommendations for other women on age of childbearing or engagement with ART.

## 9.2.4 Data Analysis

Responses from both interviews and survey comments were not combined as, although participants had been asked about similar key themes, responses were obtained in different formats. The issues arising from the analysis are outlined as subsections 9.3.1 to 9.3.13 for Group D and 9.4.1 to 9.4.13 for Survey B.

## 9.3 Results Group D

### 9.3.1 Understanding of Fertility Decline.

Participants were asked about their personal opinions on the optimal age to start a family. As they had used ART, their knowledge of the period of fertility decline could have changed from their original perception.

I suppose before we went and started to look at it, I just don't know, I knew eventually that your fertility declines but I didn't realise it was at 35 and they had already put me in the problem category because I was 37. But the obvious impact on fertility is that 35 is the tipping point where it really starts to drop. And then once you get past 40 that's the real grey danger zone. (AN)

I guess as a young child my idea was that by the time I was 30 I would have finished having my children and that probably just came from hearing aunties and older women talking. Now I understand through IVF is that 35 is the tipping point. (SJ)

Some women were unaware of their "biological clock ticking" and the optimum age for childbearing. ART was their only chance for a conception.

But from what I understand through IVF is that 35 is a tipping point where if you look at a child I guess the slope of the decline becomes a lot stronger, so it declines a lot more rapidly and a lot quicker after the age of 35. (SJ)

No, I never thought about it. And I don't know why I didn't think about it. When you get to your late 30s you don't remember

what your next goal is but maybe it was so I just didn't look into all that. I do not know. (JA)

At the age of 35 years, a relationship partner informed LL about the midlife decline in fertility, but she had dismissed the suggestion. She started ART at age 41.

And I remember boo-hooing him, just sort of in my own mind like thinking - 35? I was like, don't be ridiculous, and now he is absolutely right. But I think I just sort of decided – there's plenty of time, 35 is so young. (LL)

SJ assumed that she had plenty of time to have a family.

“There's plenty of time — 35 is so young” (SJ).

### **9.3.2 Social Factors Influencing the Timing of Childbearing.**

There are various socially based reasons why women approach motherhood in midlife and the literature highlights reasons of career, partnering relationships, financial security or educational aspirations.

“So, I guess I was quite focused on study and then building careers and things like that” (LL).

“The expectation for lot of women is to work until the mid-thirties and then you think about children because you have that work pathway you must fill” (SH).

Career and work commitments influenced some women to postpone childbearing until their late 30s and older. Nevertheless, some women found their priorities shifted with increasing age and their desire to have children surpassed their career aspirations.

Once I sort of started trying to have a family my interest in having a career just sort of left - I think I realised that it's just not a priority. I was working really long hours because I felt like

I just had to keep going up, up, up, you know, whereas now it's like, I'm not interested, not in the slightest. You are made to feel like you have to make yourself powerful and break the glass ceiling. (TO)

Some women intentionally delayed childbearing until they were financially secure.

I would try full time to have a child whereas when you're 30 you can't afford to do that – 40 you have your money so I think ideally, financially it's a better time. Unfortunately your body doesn't always think that. (JA)

Participants discussed how the absence of the right partnering relationship or the lack of a partner was a factor for them delaying childbearing.

“I travelled around the state every 3–4 weeks and didn't have a chance to form a relationship of any sort” (SH).

Well, my thing was that I hadn't found anyone worth having children with, if you know what I mean. So I think having a husband 15 years ago probably means that I wouldn't be here today, what I mean, I wouldn't be telling a story. (JA)

“I knew it was something I wanted to do, but something to do with someone else. We didn't meet each other until later in life at the age of 35” (AN).

Some women thought, upon reflection, that their search for a partner did not coincide with their most fertile years.

I think I always imagined I would meet Mr. Right and all that stuff would happen and it just didn't happen probably within those ideal childbearing years. The decision was reached and now that I do have a partner and he is supportive of trying and giving it a go, but, yeah, it's probably not too late. (LL)

I was really lost leading up to where I found my partner in life, I just didn't fit in anywhere anymore, and you are too tired to go out clubbing all the time, I couldn't figure out where to meet people. (TO)

Some participants were not focused on having a child in their prime reproductive years, as motherhood, at that time, was not imperative.

I was never interested in having kids. I don't remember really anyone that I would consider even having a family with, you know, it wasn't at that point in my head. It was never really a decision that I must have children and I must, I am getting really old and I must have them. It sort of moved from an idea into reality as I didn't have that huge expectation that I am going to have children. (SH)

"I was never one of these women who wanted to necessarily now—wasn't family, baby, husband focused. I sort of had other things going on" (LL).

"Having a career and not finding the right person until into later life and believing you can have everything done with a career and have a family. But I do think from a societal point of view we have shifted that balance a bit further than it should have done" (AN).

For some participants delaying motherhood was a conscious decision as it was not the right time for them to have a baby.

"Well, I had already discussed it a couple of years prior and decided no, and I had always wanted children badly. I knew that I wasn't ready to have them" (JA).

... and I don't know, I was consciously making a choice not to have a family, but people assume that you don't, that you are

making that choice. They ask you why you haven't and that's quite a complicated question and really personal I think. (LL)

### **9.3.3 Regrets about Postponing Childbearing.**

Some women expressed a range of regrets about lost time and opportunities to have children naturally and then engaging with ART and regretting their decision to delay childbearing.

"I think more than anything else I wish I had known more about the possibilities maybe 5 years ago. I think once the window closes and those options are gone, then they are gone" (LL).

If you could just rethink your life and not place so much importance on something that you're later going to regret, I really believe they'll regret it and they might say that they don't but deep down they will. (TO)

"...they had already put me in a problem category because I was 37. I wished someone had said something to me earlier on that as a problem point" (AN).

One participant suggested that even her family doctor of 20 years, did not initiate a conversation around fertility; rather, a past boyfriend informed her that she should have a child by the age of 35 years.

"It might have actually rung some bells or something, but no one talks about it" (LL).

### **9.3.4 Experiences at the Infertility Clinic.**

Some participants described the effects of medical intervention. Some women described their experiences in philosophical terms and the lasting impact ART had on them.

"I keep asking myself all the time you know, what have I ever done to deserve this — not being able to have children" (JA).

“...perhaps it’s kind of changed me in nice kinds of ways. I wouldn’t have thought that way had I not gone through the experiences I had” (SJ).

I am probably more appreciative with my friends like the true friends. As I say, it’s robbed me of my confidence as a person. So definitely it has changed me. But I am hoping in the end it will be for the better. (TO)

One participant, who was a health professional, commented on her interaction with counselling provided at the at the infertility clinic.

All clinics need better and more focused counselling support. As a mental health professional the level of psychological support was out of date and tokenistic at all stages.

### **9.3.5 Expectations of ART.**

Women would naturally have an expectation and hope that their treatment cycles would be successful. However, data showed that, for some women, their hopes were not realised. Several participants reflected on the changes in their expectations of success over time. Expectations may be heightened before the start of their treatment, but expectations of a live birth may decline if repeated cycles unsuccessful. Many midlife intending mothers will not conceive despite having expectations that they would conceive on the first few cycles of ART. Women may rely on ART as a fall-back option if they cannot naturally conceive.

“...the expectations, are incredibly different to what I started to what they are now. My expectations are now that I guess the reality of this that we probably come to accept that this may not happen” (SJ).

“People don’t realise when those ones are saying there’s always IVF, okay, that’s the last resort” (JA).

“We didn’t have a lot of knowledge of anything then and so we obviously had it in our heads that this is going to be a really, really quick process” (SJ).

Success for many women would be having a baby, but for AN, it was just getting pregnant.

“My feeling would be that for a success in IVF my hurdle is that 19, 20-week morphology scan. Having gone through it I would draw my successes back a little earlier” (AN).

Some women had unrealistic expectations that ART would be able to help them conceive. Some women had hopes that they would quickly fall pregnant, but for some this was unrealistic.

Well for me, I think it’s got a bit to do with that you can do anything, you can do anything anytime, and science and technology is on your side; if you wake up and you are 40 and you don’t have a baby, someone will help you. You just went to a fertility specialist and a few months later walk out pregnant. I think I assumed it was that simple. I always assumed I think because I’ve achieved everything else I wanted to achieve. Sadly, it is not. (LL)

Look, beforehand I really thought that I would walk up to IVF and it will just happen. I just trusted that it was just going to work. So I probably thought, 95% chance I was going to fall pregnant. I thought you walk in, walk out. But I did expect it to be sooner; I wouldn’t have expected it to be so this many years ago. (TO)

I think it’s one of those things that once you make up your mind to give it a try and there is certainly a level of determination and well, I’m going to be different to everyone else and prove everyone else wrong. I assumed that if you achieved a pregnancy and all things were going well, again that science



and the medical profession would step in and you would achieve a live birth. (LL)

My expectation at the outset was basically the same before and the specialist's opinion largely that was we were going to get pregnant in no time. So if you are a woman under 35 and going to seek fertility treatment, you know they're going to be saying, you will be pregnant in no time and so I guess at the end of the day that was something I learnt really early on. (SJ)

Several participants said they were not given realistic information on their chances of pregnancy and that infertility clinicians should give an honest indication of the chance of a successful pregnancy.

No fertility doctor should ever tell you that you will be pregnant in no time, because they can never really know — that just causes a lot of trauma for the person. It would be nice for a specialist to be able to say, 'I actually don't think your chances are very good.' I have never once heard anyone say that to me. (SJ)

At the end of that first consultation, he [clinician] was so sure that it would all be OK. I was given the impression that all would be quite easy and so his parting words were 'Let's get a baby on board and have like that sticker at the back of cars.' So it seemed to me to be really positive and sort of like it's going to be a snap, let's just get this started. I can make things happen when I want to, so if I want a baby, I'll have a baby. (LL)

A diagnosis of idiopathic infertility can be frustrating for women who need a clinical explanation of why they are unable to conceive. SJ had an expectation that not only would she have a baby but also the clinicians would be able to provide her with a medical diagnosis for her infertility. Her expectation had not been realised.

My expectations haven't been met because my expectations are that I should have a reason why I am not able to get

pregnant. I still can't understand that given all the technology we have today around IVF that people don't have diagnosis of unexplained fertility. So, all of that hasn't really met my expectation I guess. (SJ)

Some women's expectations of a healthy baby were not realised, and this was a bitter disappointment even for women such as TO, who had her first child through IVF and experienced secondary infertility.

I seem to always have such high expectations of myself. So, when I started the journey of trying to have a family, for it not to happen as I had planned it to happen, it was all a big shock for me. (TO)

Even though you try to be logical and measure your own expectations, we'll keep them realistic. I had created, obviously, an expectation of a positive outcome, so when there is a negative outcome the disappointment is quite strong. (LL)

### **9.3.6 Impact of the media on women's perceptions of ART.**

Expectations of a live birth could be influenced by personal preconceptions or by images portrayed in media or marketing campaigns. Participants agreed that media gave an affirmation of success rates which may elevate expectations for a baby. Furthermore, participants decided that the negative aspects of ART for older women were not frequently discussed in the mainstream media thus giving the perception that ART is successful for older women.

"So I think the media does give women incorrect information of the success of IVF for the general public" (SJ).

But for women like 40, I think the media creates a very positive spin on them. You don't really hear the downside. The positive is always reported in the media. No one expects them to go into the gory details, but maybe that is not the type of content that women's magazines want to portray because they are trying to sell a certain dream or a lifestyle or whatever. (LL)

I see things in the media that might create a false expectation of a woman's ability to actually conceive a child whether it's her own, got through her own egg or even a donor egg at a certain age. (LL)

"I haven't heard a lot of stories in the media for IVF, and what I've have it's always been positive. You don't hear anything negative about this sort of thing" (JA).

"The one thing I remember hearing on the radio is [that] 99% developed a pregnancy in one in three cycles. It catches my ear every time, so I think, are you kidding yourself" (TO).

I think, for people who don't know very much about IVF, the media gives women the completely wrong picture and, again, what you will see in the media is probably all of the successful stories and they're probably based on celebrities and so forth. What they don't put in there is a person's individual circumstances. (SJ)

"I said the media does give women a perception of IVF, I think often they publish the good stories and the good outcomes" (SJ).

"But the media does also show a lot of older women actually having babies quite later in life. Again, they're obviously not reporting on all of the women who are unable to have children later in life" (SJ).

"The impact that those media stories have on me is that I have often felt quite devastated by those stories" (AN).

"I heard that you are susceptible to cancers, ovarian and breast cancer because of chemicals and hormones. But my desire to have a baby was stronger than the fear of getting cancer" (TO).

Women's perceptions of the success of ART may be influenced by media depiction of older celebrities who have a baby. Celebrities may appear as role models giving the impression that older women do not have difficulty with conception. However, it is often

unclear whether older celebrities have conceived with their oocytes, or donated oocytes from younger women, or used ART.

I think that if there is a celebrity who actually has an IVF baby, it looks as if that person has undergone IVF and done one cycle and they have a child, but it is very possibly they may have done 10. Those other previous cycles are probably not going to be mentioned. (SJ)

You think if she can do it and I am only 35, then I can do it too or I am only 40 and all the personalities overseas like actresses that are 42 and having a baby... that probably gives off the message that that's OK too. (TO)

Some of the women had read an article in the Australian media about a woman who had given birth at the age of 50 years. However, the article failed to declare that the mother was hypertensive, an insulin dependent diabetic who required a LSCS at 35 weeks gestation due to concerns of preeclampsia (Rani et al., 2015). One woman, in particular, was disappointed in the content of the article.

It was just a very glossy article about how happy she was, but it did not mention anything about her journey or what she'd gone through or whether it's her own egg or a donor egg or anything like that. So I think it's just very one-dimensional...it's all about the outcome. (LL)

SJ suggested that media focus on younger women delaying their childbearing with the assurance that frozen oocytes may lead them to future disappointment, as there is no certainty of success.

In the media, I think they were just newspapers saying that people may perhaps be advocating for women to freeze their eggs at a young age with, obviously, the promise that later you can then have your career and do whatever you want to do, travel, and have your children later. And my understanding from the whole idea is that it doesn't quite work like that and there is no great statistical evidence that egg freezing is any

benefit. Stories like that in the media could make somebody think, well, I might just freeze my eggs and then I have got another 10–15 years or something like that. (SJ)

“With young women, you know, when you think about the media as well, it is something reporting what the average time — what are the average ages that women are now having children” (SJ).

Participant JA did not agree that media portrayal of ART influenced her childbearing intentions.

AN was undecided as to the influence of the media compared to the influence of peer group.

I think the media has an involvement in that sort of cultural influence of when it is a good time for people to have children. I feel like the people I was around and the communities I was in had a much bigger impact on me deciding when to have children rather than in the media. (AN)

### **9.3.7 Understanding the Risks**

Some participants had great faith in the ability of science and technology to deliver them a healthy baby and were unaware of possible medical complications in conception and birth, and the risk of congenital anomalies.

“The publicity about IVF never shows you the failure associated with it and I certainly haven’t seen about side effects beforehand” (AN).

Midlife intending mothers may be unaware of the health risks to themselves and offspring when having children later in life. LL suggested that this lack of information opened women to potential unknown risks of ART.

Just providing that information or some more reality in reporting so that women actually understand the possibilities, percentage wise; I think that’s not really discussed, some of that potential

health and sort of issues for the child. I don't think that's widely discussed or mentioned in the media. (LL)

### **9.3.8 Commodification and Marketing of Motherhood and ART**

Expectations of a successful outcome can be elevated by promotional material supplied by infertility clinics and pharmaceutical companies that manufacture ovulatory drugs. Such information may not communicate the realistic success rates of ART or women may misunderstand the information from their clinician.

“Sometimes when you first go to a clinic, you're given enormous odds, positive odds over 90%” (JA).

“I think they are very evasive about answering specific questions about success rates.” (AN)

I think it's a bit biased towards positives of IVF and they sometimes overstate success. If you read everything, it does say the success rate is about 30 percent, I think that it's a bit biased towards the positive, but it is business. (SH)

One support group member had undergone eight years of ART from the age of 32 years without success. She felt she had no psychological support from the clinic, especially when she and her partner decided to remain childless. She expressed her concerns about the business of ART and profit making.

They are more interested in the couples who have babies than the ones who fail! It has become a moneymaking business; they implied that all couples will take a baby home! When you are no longer a paying customer, they don't want to know you. (SG)

SJ also felt that the pictures of young mothers in marketing campaigns supported her belief that she would have a successful cycle.

...even the pictures they use, I mean they've all got beautiful brand-new babies on there. Not all of them publish, I believe,

the actual success rates, I know some clinics do and some clinics don't. But, definitely, the marketing information — it does change a person's impression of IVF technology and success rates, particularly success rates. (SJ)

I think it's tilted more towards the possibilities and the positive outcome than the reality of the impacts of it, the journey, and the possible outcomes or the lack of outcome. So I felt they had a bit of a sales spin to it that was, you know, what can we do for you. It is obviously from the pharmaceutical suppliers, you know, look what we can do for you. (LL)

Some participants felt that the clinic and the clinic staff elevated their hopes. Media or promotional material from infertility clinics could raise their expectations of success. SJ started ART when younger than 35 years and had undertaken 17 cycles.

If I look back at even us in the early days, I mean we didn't think we would be at the point of having 17 cycles later. We were always under the impression that we were going to be pregnant rather quickly, and all of that information and while we were reading, that the success rate was good and the fact that I was under 35 and so forth. It would be nice for a specialist to be able to say, I actually don't think your chances are very good and I have never heard anyone say that to me. (SJ)

The promotional material from fertility clinics can shape women's perceptions of the success of ART.

They [infertility clinics] talk about how many IVF babies have been born in Australia, but what about the bit of information they don't give you is that they don't tell you how many IVF cycles did it take to have that number of babies born (SJ).

"The publicity about IVF never shows you the failure associated with it, and I certainly haven't seen information on side effects before "(AN).

Once I decided I was going, I probably didn't read a lot of their information. I would have seen was that I think it was a 95%

success rate that they were going to get you pregnant within, a certain number of cycles. That's like all I caught on to and that's all I believed in — all the other stuff behind the scenes saying no. (TO)

TO suggested that no one told her that it would take more than one cycle to have a child. However, TO felt that her doctor maintained a positive outlook which was also for his benefit.

They are so positive — their job is to keep you optimistic, I think. I don't think it's a sell job that he is optimistic, I think it's just that he needs to maintain that, otherwise he probably has a crushed life, you know his job is to try and maintain his own sanity, he needs to be optimistic to people. (TO)

### **9.3.9 'Calling it a day': When and How to stop ART.**

The financial, emotional, social and relationship aspects of infertility treatment impacted on some participants. The decision to stop ART without having a child can be difficult. For such women, there is no hope of children and they must rethink their life plan and aspirations. Of the women who stop ART without having conceived, most do this because of emotional stress or poor prognosis' (Brandes et al., 2009).

One respondent who had had nine ART cycles agreed that the cost of ART would be a factor in her continuing treatment.

You really don't get a lot of support from the government I think. The Medicare thing, they changed it. It was quite good before that, well, it didn't feel as taxing on your savings until they changed that and then that really hurt. (TO)

Financial constraints can be a reason for women stopping treatment as the out-of-pocket expenses for a cycle and options such as preimplantation screening can be expensive.



“I am sure for a lot of people financing would have to be up at the top of the list somewhere” (SJ).

“Finance would be a big one. Someone was telling me they were in debt because of IVF” (JA).

“There is a lot of outlay, which you have to fund for quite a while before you get money back as well” (LL).

Women spoke of the emotional impact of ART being a reason for stopping treatment.

“...he (partner) was struggling with the emotional impact of it (IVF) had on me. We were coming to a point where we were going to say this isn't worth it” (AN).

“I think the emotional cost to someone having those highs and lows constantly could definitely influence a person's decision to stop” (SJ).

That depends on age I think and the reality around whether or not continuing is going to pep up the potentials of positive outcomes. So I think it's quite age dependent and depending on your circumstances to why you are there. Desperation, well, desperation I guess or the ability to adopt or something, so other choices. So I think that once the decision has been made that people want a baby. If they can have a baby in other ways through adoption or something like that, then that's obviously going to be the trigger for them not continuing to peruse IVF. (LL)

“For me, I want to sort of reach a point where I say, okay, you've got to let it go and I sort of want to get on. If it's no then that's okay, unless you've sort of at least made the decision to get on with other things” (LL).

After a miscarriage and six back-to-back ART cycles TO said,

I just couldn't give up. Finished one cycle and it didn't work, I cried my eyes out, went on the next cycle. I don't know how to say when I am going to say enough is enough. I am hoping, I guess, in my heart of hearts that this one, you know. I see myself with the two children — I feel I could be happy with that. But you know, I don't know how I'm going to cope if it's the only one. I have a baby and I still can't stop. We are in debt but we are still going. (TO)

One respondent discussed how the three years of ART had taken a toll on her partnering relationship and this was a factor in her discontinuing treatment. Wollett (1996) suggests that when the decision is made to stop treatment, rather than blaming treatment, the blame can shift to blaming the woman for a lack of perseverance.

Emotionally and relationship wise it was taking its toll and we realised we were coming to a point where we are going to have to say that this isn't worth it as we are the most important thing in this relationship. We got to a point where we were almost getting a separation. (AN)

SJ cited her reasons for stopping after 17 cycles of ART as financial and emotional. However, concerns about the potential health risk of another cycle were her main deterrent.

“And I just kind of think how he would feel if something happened to me or I got sick because of trying to have another child when we actually have got him so I mean that is a factor that kind of influences my decision” (SJ).

JA felt that her expectations of the technology had not been fulfilled, as she had not had a baby. However, she had personal reasons for not continuing with further cycles.

No I haven't got a baby yet, it's got to happen soon. I'm not prepared to give up yet. Finance would be one thing, I think maybe the disappointment the constant no's and my husband

is 10 years older than me, he is saying I don't want to be an old dad. (JA)

Some participants found it hard to stop treatment and hoped that the next cycle would be successful. Some had done everything possible for pregnancy but felt there was no clear endpoint to treatment. These women had anticipated decision regret, as they did not want to stop ART in case their next cycle was successful.

“Because I achieved the blastocyst I sort of feel like I've got a step closer so now I think that probably we'll have one more try” (LL).

### **9.3.10 Emotional Roller Coaster.**

'Emotional roller coaster' was a term used by some participants to describe the swings of emotions from hope to despair if the cycle was unsuccessful and the hormonal effects of the ovulatory drugs.

I think I didn't expect the emotional stuff, although I've been warned. Oh it was bad. Because there was one drug they put me on the very first time and I sort of became wimpy. I have been crazy and said I'll never do that again and then with this new clinic that I tried hasn't sent me wimpy this time. It must have been stresses in my life at the time as well. I didn't realise at first it was ever so much of an emotional a roller coaster. (JA)

“Emotionally the brain is just not prepared – you still expect it to work. Mentally consuming and it's really hard not to think about that every minute of the day. I just couldn't have even anticipated the emotional toll associated with it” (AN).

Some suggested that the waiting time after the embryo transfer until a pregnancy test was a time of heightened emotions eventuating in either joy or despair. TO was anxious after

oocyte collection procedure, as she had lost ART-conceived triplets at 24 weeks gestation. She found unsuccessful cycles were difficult when her oocytes failed to fertilise.

Then you get the negative result and you hang up the phone and burst into tears. I was always crying at the clinic as I am really emotional. I just want more, you know, the journey is not done for me. (TO)

### **9.3.11 Taboos and Secrecy.**

Some women do not freely discuss their decision to have a child or their ART journey. Some women considered that ART is often a taboo subject with their friends and family. Women may be unaware of the low success rates for midlife intending mothers as shown by some of the responses. Zoll (2013, 2014) suggests that taboos are reinforced by infertility clinics as they do not wish patients to discuss their infertility or the failure of ART to solve their infertility. The absence of accurate information makes the success stories in media misleading.

“I don’t think that’s talked about, and I think it probably should be. And I think friends should be more honest with each other around things like that” (LL).

I think there is a bit of a taboo, people don’t want to talk about it with their friends or with their family and certainly wouldn’t want to participate in something like this because they might as well talk about things that are personal — I’m not sure why I think there is a taboo around this subject. I think women’s ability to have a child, to be fertile is not something that women feel comfortable talking about with their friends necessarily even with their health professionals. (LL)

“Girlfriends don’t ask each other about when they are having like why they don’t like having a baby, none of mine do. I cannot even remember one friend of mine who has talked about her fertility” (LL).

“My friends hear my story. But other than that, when you are going through the process of IVF most people don’t know your story” (SJ).

I didn’t even know that my cousin had a problem until she found out that I had a problem and that’s probably because my parents are both from huge families — it’s not a dirty secret that I am doing IVF. (TO)

“It’s, to them, like a taboo subject, and I know women in their fertility and their ability to mother and all that type of thing is very deeply engrained in literature and art history and the feminine psyche” (LL).

AN found an important emotional support tool through an online support group with other women undertaking ART.

I didn’t have to talk to people in my normal world, I had people who understood all the stresses of IVF and that we could post and chat to each other. It helped me understand a lot more about the drugs... and how you deal with failure and how you deal with moving into the next one. (AN)

It was mentioned that women are reluctant to discuss issues with other clinic patients who might be empathetic. Women were secretive about the outcomes of their oocyte transfers and the results of their cycles.

IVF is, sort of like, it’s a secret fraternity. If you walk into a clinic and you see 10 other couples, not one of those couples will talk to you. Some would barely make eye contact. And I don’t know why. I don’t think it’s shame; I think it’s that’s people are afraid of the success of others in my opinion. (TO)

“I didn’t want to be around other people who are doing IVF and didn’t want to be around other infertile people because I didn’t want to be faced with it” (AN).

### **9.3.12 The Journey.**

Whether the treatment was successful or not, women describe their journey as an often difficult and something they will not quickly forget, and AN and LL found aspects of their experience to be positive.

I think it has made me a better person as well because it has made me look at how to deal with more hurdles and get over those. It has made me incredibly sensitive about not making judgement on childless couples...it has opened my eyes to the world of infertility because I never expected to be in that place. (AN)

It's probably made me more aware of the possibilities for other people who don't appear to have made choices around childbearing. I think it's actually been quite a good thing for our relationship because it sort of made us focus on what we want and it's been quite good. (LL)

### **9.3.13 “Don't Wait for IVF”: Recommendations from Participants.**

Women who had used ART had the following recommendations for those who may be contemplating ART or midlife motherhood. Some of the women were clear that they hoped their recommendations would be available to other women as a result of this research. No woman in this study recommended ART or delaying childbearing; their recommendations were to the contrary. They advised other women, if possible, to have a natural conception when fertile and not to rely on ART as a fall-back option. Women's recommendations for other women making decisions on timing of childbearing are detailed below and in direct quotation from the data, as their message is more poignant when in their words.

“Women thinking they can wait until 35, I don't know, it's a dangerous game to play with your body” (TO).

“Cut to the chase, do it by the time you're 35 and do it naturally if you can” (LL).

“Don't rely on it [ART].... some more information about the reality of how likely it is” (LL).

“Obviously, don’t leave it too late... if it’s an age-related issue that 12 months delay could have been precious time where perhaps your eggs were of better quality” (JA).

The following recommendations were for women who were worried that taking time away from a career to have a baby could be disadvantageous for their careers.

I would never, even for my daughter, want her to wait as long as I did. I would really like for her to have her life in order that she has a good comfortable career, job, whatever that she understands that can be put on hold and you can come back to it, you’re not old and dead at 40. (SJ)

You still may be 35, look at the time you have for a career from there. You are grounded; you are in a better position at 35 to have a career then you are having that career when you are young. I will be telling it to my step-daughter, I will be telling it to our daughter. (TO)

“I would like to change people’s perception about having children in their late 20s, early 30s, that’s when I think we should be doing it” (AN).

Women who had used ART had suggestions to disseminate warnings to their peers on the timing of motherhood. They suggested that these discussions should be initiated among young women during their educational years or whilst employed. Social media was suggested as one medium for public health education.

“Maybe Facebook — it will probably catch you. I don’t know, there must be some sort of women’s network” (TO).

“It’s an opportunity in their senior years to introduce it to the curriculum about the cycle of life, I mean, the real cycle of life” (LL).

There could be some sort of information pack and there would be stories of women who of various ages or something like that

so that you actually know where you're heading and then it might help you make your choices. (LL)

"But I think more information, more balanced information would certainly assist in people if they decide to continue or give then a measure of reality around what the possible outcomes might be" (LL).

...but for your average person to be looking in a reproductive journal isn't going to actually get to the people that would have needed to see it at the right time. ..If you're trying to get it to a mass amount of people I would say the newspaper would probably be the best bet...but the health section is probably read by a majority of people. (SJ)

"TV advertisements" (JA).

## **9.4 Results from Survey B**

Survey B comprised 68 women, and of these, around half the women chose to provide comments in an open question format provided as an optional question in the online survey. These participants were aged 35 years or older and had a range of engagement with ART and a mixture of success and failure to conceive. Survey B participants who left comments were coded SG.

### **9.4.1 Understanding of Fertility Decline.**

As with Group D interviewees, some women did not intentionally delay childbearing and were midlife intending mothers due to personal circumstances.

"I did have some belief that it was still OK to have a child after 40. I now believe this is truly not the case" (SG 4).

"I have to admit that I never imagined that I would be 39, single, and having to rely on an anonymous sperm donor in order to have children. I want a man" (SG 11).

I married at 28 and began trying to get pregnant. Altogether we had 10 attempts with two births at 37 and 42. I did not choose to have children late in life; it was thrust upon me by infertility



issues beyond my control. ...do not forget those of us who have children late in life not by choice. (SG 19)

#### **9.4.2 Social Factors Influencing the Timing of Childbearing.**

Participants supported the common theme of midlife mothering due to difficulties in finding a suitable relationship partner and waiting until they were financially secure.

“Unfortunately I did not find my life partner until I was 40. That is the only reason I delayed having a baby” (SG 4).

“If had found my sole mate and married earlier in life, then I would have attempted to have a family earlier” (SG 26).

“We delayed starting a family until we felt we were in a secure financial position” (SG 34).

#### **9.4.3 Regrets about Postponing Childbearing.**

The theory of anticipated decision regret suggests that women try ART so they would not have regrets later in life that they had done not all they could to have a child. The wish to avoid regret was suggested by some participants.

At least I could say that I tried everything and would have no possible regrets later in life. It was a difficult decision that I spent six months thinking about to make sure it was the right decision for me. (SG 11)

“...so that at least I could say that I had tried everything and would have no possible regrets later in life” (SG 11).

I have found going through IVF treatment the most difficult thing I have ever experienced. We had our daughter when I was 34 and have tried for the next five years to have another child. I feel I will never get over the emotional trauma of not being able to have more children. (SG 16)

SG 33 expressed regret that health professionals did not advise her of the low statistical chance of a birth after she terminated a pregnancy conceived with an unwilling partner

when aged 41. It was suggested to her that there was no reason why she could not have a family when her partner was ready.

“I’m struggling with the outcomes of ignorance and poor (but seemingly politically correct) advice (as in, You Can Have It All” (SG 33)

#### **9.4.4 Experiences at the Infertility Clinic**

Overall the participants found their experiences of ART to be a difficult and for some women a negative experience, however others found their experiences to be more positive.

“The two-week wait was the most difficult part and felt that extra support would have been appreciated during this time” (SG 8).

Some ART clinics display photographs of ART-conceived babies in clinicians’ and infertility clinic offices. For SG 9, this visual assault and her eight failed cycles exacerbated her distress and sense of personal failure.

Every month that went by and I continued to be unsuccessful, these reminders were like someone sticking a knife into my heart and inflicting more pain and sadness than I was already enduring. This shows you how insensitive these health professionals can be. (SG 9)

Many women had a positive experience at the fertility clinic.

“Overall found it to be a positive experience despite having negative outcomes and a cancelled cycle (SG 13).

“When I ended up being treated by the fertility professionals, I can only say good things about their assistance and support” (SG 33).

SG 15 suggested women should inform themselves about their fertility options rather than relying solely on their clinician.

“Tell other people who are trying IVF to know what options are available; don’t just listen to your doctor — the QFG newsletter kept us informed of new technology” (SG 15).

Participants suggested clinics should provide a greater level of psychological and nurse counsellor support.

The clinic provided excellent support in terms of medical procedures, but the psychological support was limited. I had a good relationship with my fertility doctor but I was not able to talk to her directly about questions or the receipt of results. I was not at all happy about receiving results of my treatment from receptionists. (SG 17)

“There was the lack of support from the nurse counsellors during my treatment in general as I hardly had any contact from them during my journey” (SG 20).

“Once you have a pregnancy everything is great, however if you have a miscarriage there is very little emotional support for the couple, no one checks how you are going” (SG 30).

#### **9.4.5 Expectations of ART.**

Women reflected on their expectations of a baby through ART and some felt that their expectations were unrealistic.

“I had treatment for eight years without success. I started when I was 32, I continued treatment as I was given (false) hope that I could still have a child” (SG 9).

I probably did have unrealistic expectations of success from IVF, mostly because two of my best friends had success first go. I remember being reading or being quoted a 40-50% success rate for ‘fresh’ cycles and 30% for ‘frozen’ cycles. (SG 17)

“We were very naïve — I think we didn’t really believe the statistics would apply to us” (SG 33).

#### **9.4.6 Impact of the Media on Women’s Perceptions of ART.**

Some participants believed that the portrayal of ART success in media was not a balanced view for women of all age groups.

I thought my fertility [sic] might reduce but I never did I imagine that it would become almost non-existent, particularly with all the media hype about women having babies in their 40s with friends backing this up with you’ll be right, women have babies at 40. (SG20)

“If I hear one more story about these 40-something celebrities having babies ‘naturally’, I will scream” (SG 22).

The media and other publications focus on the positive outcomes of ART and women over 35 years having babies. It is not a balanced and objective approach in accurately portraying the facts, but then the negative stories wouldn’t generate revenue return. (SG 24)

#### **9.4.7 Understanding the Risks.**

Risks of undertaking ART include risks from the ovulatory drugs and for women aged over 35 years there is an increased risk of a child with an abnormal karyotype compared with younger women.

“I wish the stats had been explained more often. It’s hard to take in all the information about the drugs and side effects, as well as stats about your chances” (SG 27).

#### **9.4.8 Commodification and Marketing of Motherhood and ART.**

Some women felt a lack of support after they registered with the clinic and felt that having a baby had become commodified.

They are more interested in the couples who have babies than the ones who fail! It has become a money-making business

that implied all couples will take a baby home! When you are no longer a paying customer they don't want to know you. (SG 9)

“My fertility doctor's response to a failed cycle was to ask when I wanted to start the next one” (SG 17).

#### **9.4.9 “Calling it a day”: When and How to Stop ART.**

Deciding to stop ART was mentioned as a difficult decision as women may believe that another cycle will be successful. One participant suggests that psychological support was not available when making the decision whether to continue or stop treatment.

“Due to the latest poor outcome from my IVF treatment, I am hugely undecided if I will have another attempt. The disappointment is also very hard to bear” (SG 4).

“After many years of heartache we decided that our life was to sadly be childless! There was no psychological support from the clinic; we had to face this decision alone” (SG 9).

“I am not ready for that conversation yet although I am starting to feel we may need to do so soon” (SG 12).

“I feel it can also become quite an addictive treatment, i.e. knowing when to stop...maybe this cycle will be the one” (SG 13).

SG 5 used ART as her relationship partner chose to leave the relationship rather than go through the expense and stress of ART. Despite these impediments she chose to continue until she was successful.

“I would never have stopped til I'd had at least two children”. (SG 5)

One woman was advised to stop autologous cycles but felt her doctor supported her decision to continue treatment despite a having negligible chance of success.

“..he kept going as long as I needed him to and that was hugely important, because I needed to make the decision to

stop rather than have someone make that decision for me”.  
(SG34)

#### **9.4.10 Emotional Roller Coaster.**

As SG31 described, the decision to stop after four ART cycles was averted when she conceived. She understood the difficulty when making the decision whether to stop ART or continue. SG 19, SG20 and SG 31 described their ART experience as like being on a ‘roller coaster’.

“...when you are on an emotional roller coaster most of the time. I do have times when I am still quite affected by the childless that I must now endure (SG19).

“... you are on an emotional roller coaster most of the time (SG20).

“It is an all-consuming process and, once on the roller coaster, state very hard to make the decision to jump off!” (SG31).

Women described the emotional toll of ART treatments.

“I found IVF treatment very difficult at times however the emotional side of things was far more difficult than the treatments (SG 1).

“I know of so many who are heartbroken through constant failure (SG 2).

“The public don’t realise the huge correlation between marriage breakdown associated with infertility and single women trying to conceive” (SG 5).

“I believe we are very realistic about our chances and find each cycle of IVF difficult when you get a negative result but we are strong enough to try again” (SG 17).

SG 24, who had five full cycles and five frozen transfers with no success, commented on the emotional toll on her marriage.

“...my marriage broke up and I believe this had something to do with it “(SG 24).

#### **9.4.11 Taboos and Secrecy.**

SG 11 supported the belief that some women found discussing their engagement with ART was not something they openly discussed.

“My closest friends know how I came to have a baby, but I don’t go around telling everybody because I don’t want to be judged (SG 11).

#### **9.4.12 The Journey.**

Whether the treatment was successful or not, women describe their journey as an often difficult and something they will not easily forget.

They told me I had a 10% chance of it working. I gave birth at the age of 41 and a half. There isn’t a day that goes by that I don’t thank God for my opportunities and the baby I’ve been given. It was the right decision for me (SG 11).

“I know many families have had more traumatic experiences with infertility than myself, and I feel blessed to have my daughter, but I do feel the experience of infertility has dominated my life for the past six years” (SG 17).

As a result of my journey, I find it very difficult to go anywhere near Watkins Medical Centre these days and whilst I am getting much better, I do have times when I am quite affected by the childless state that I now endure (SG 20).

“I am now pregnant...it seems worth all the stress and heartache however, I haven’t forgotten how hard it was and everyday I am grateful” (SG 36).

#### **9.4.13 “Don’t wait for IVF”: Recommendations from participants.**

Women’s recommendations for other women making decisions on timing of childbearing are detailed below and in direct quotation from data, as their message is more poignant when in their words. The views of these women were similar to those of Group D.

“I tell any young women I meet not to leave their babies till later in their lives. The possible complications and emotional pain associated with that are not worth the wait” (SG 4).

“I did have some belief that it was OK to have a child after 40. I now believe this is truly not the case” (SG 4).

“Women need to be warned to start trying to conceive before age 30 so they can complete their families, not given the impression they can wait until closer to 33 or so” (SG 5).

“I think there needs to be more public awareness about ART” (SG 10).

“If you can do it now, don’t wait for IVF” (SG 13).

“I tell any young women I meet not to leave their babies until later in life. The possible complications and emotional pain associated with that are not worth the wait” (SG 16).

“ART is no guarantee of a child, and young women should not have the attitude of delaying a child because they think they can always have IVF. Definitely a misconception” (SG 29).

### **9.5 Summary**

Responses from both participant groups revealed a complicated emotional journey for women undertaking ART. There lies an undercurrent that highlights the difficulty of trying to have a child and the far-reaching impacts of the ART process. Women who had a baby considered themselves lucky. Despite their success, these women, as did their less fortunate peers, found the process financially, physically and emotionally challenging.

Women had various reasons for delaying childbearing and lack of a relationship was a typical response. Some women found they had bypassed their fertile years by trying to be financially secured before having children. Others believed they were not emotionally



ready for motherhood until later in life, and when they tried for a natural conception they were unsuccessful. Many women felt they could have children in their late 30s and early 40s, and expressed regret that they were not aware of the limits to their fertility or chose to ignore warnings from friends.

The expectation that they would conceive was high and many participants were surprised to find they were unsuccessful. Infertility clinicians who were enthusiastic about their chances of success heightened women's expectations. The assumption of ART success was reinforced by information from the fertility clinic and the media's depiction of babies born to older women, particularly older celebrity mothers.

Some women expressed the view that the marketing of ART bypassed some critical information for older women as they were given an impression of high success rates. Some were not made aware of potential risks to the health of mother and baby and the higher-than-population risk of a genetic abnormality in ART-conceived infants evidenced in some studies. Some women felt that ART was commodified and they had become part of a money-making business. On the other hand, many women were satisfied with the infertility clinic and did not discuss such feelings.

Some participants discussed a lack of emotional support during treatment and when contemplating whether to cease treatment. Some women did not want to experience regret that they had not done all they could to have a child.

These women felt this research could facilitate an improvement in community knowledge of the age of fertility decline and realistic success rates of ART. After having used ART, their recommendations detail the messages they believe should be passed on to younger women. Women think the medical profession and media can improve the understanding of these issues in women of childbearing age.

Women found ART to be an arduous journey that consumed their lives. These findings are juxtaposed in Chapter 10 with the quantitative results from Chapters 6, 7 and 8.

## **Chapter 10: Discussion**

The discussion reports on responses from women who had used ART from the support group, the interview group, and males and females in the community who may not have used ART. The findings are reported as a generalised view of ART in Australia. Women who had used ART had significantly different views to the general community regarding older women accessing assisted fertility services and fertility decline. The findings indicate that this is a complex issue and it would be simplistic to imagine an easy solution. Many factors determine women's decision making however, accurate information is required for informed decisions to be made. This chapter outlines the key findings and responses to the research questions, and recommendations to young women from those who used ART.

### **10.1 Introduction**

This research aimed to ascertain the beliefs, expectations, and experiences of a cohort of women undergoing ART in Australia as well as community understanding of fertility and ART. Two groups were statistically compared: a group of men and women in the community (N=1243; Group C) and women who had engaged with ART (N=68; Group B). Qualitative data were gathered from interviews with Group D (N=6). A broad range of data collection methods was utilised and allowed in-depth analysis of the research topic. Qualitative and quantitative data were analysed and the findings reported in Chapters 6–9.

The concepts described in this research are of interest because they challenge the depiction of women intent on delaying childbearing for career or financial enhancement. ART promotional information and media representation may give some women the impression that medical technology can override age-related infertility. The dominant image is that ART is a successful technology. So when ART fails women have limited resources to understand and manage that situation (Throsby, 2004).

ART does not cure infertility and, in the case of age-related infertility in older women, it cannot reverse age-related chromosomal changes in their oocytes. The consequences of such genetic changes are to reduce the chance of fertilisation and increase the risk of miscarriage. The previous chapters describe a somewhat challenging journey for women

who undertake ART. Whatever the outcome, ART treatment can be intensely emotional and challenging.

## **10.2 Research Questions**

The following eight research questions are addressed within sub-sections 10.2.2 to 10.2.7.

1. What are the views of women who have engaged with ART about their clinic experience?
2. What were women's expectations of the success of ART?
3. What are the views of women involved with ART on women's age-related fertility decline, childbearing decisions, the success of ART, and impact of media and marketing on childbearing decisions?
4. What are the beliefs of the community towards women's age-related fertility decline, childbearing decisions, success of ART, and impact of media and marketing on childbearing decisions?
5. Do social factors such as career and work, educational attainment, financial security, health or partnering relationship influence women's childbearing intentions?
6. Is there a perception among the general population and consumers of ART that infertility is medicalised and its treatment commodified?
7. What are the social and psychological impacts for women using ART?
8. Do women who have engaged with ART have recommendations for women in the community regarding the timing of childbearing and ART?

### **10.2.1 Age and Education: the IVF Support Group**

The support group comprised women who ranged in age from 32 to 54 years and had experienced ART; many were still undertaking treatment. Education levels of the support group participants and their mothers were compared. Participants were mostly educated to a graduate or postgraduate level and were mostly in full-time employment. By contrast, most mothers' of the participants had a secondary-level education and fewer were employed outside the home. Women with higher levels of education and who are employed are more likely to delay childbearing and marriage (Rindfuss & St.John, 1983; Stolka & Barnett, 1969; Summers, 2003; Weston et al., 2004) and have a greater level of

childlessness compared with non-tertiary educated women in Australia (Miranti et al., 2009). Most participants were conceived when their mothers were aged 21 to 30 years of age, whereas all the participants were trying to get pregnant at least 8 and up to 17 years later than their mothers, a noticeable delay within one generation. Women today, are in a new context for mothering and it appears that they are not following the childbearing patterns of their mothers and grandmothers due to recent demographic changes.

Older mothers tend to be in stable relationships, educated, and have stable careers (Billari et al., 2011). The age at which women start their families is a factor in smaller family size (Australian Bureau of Statistics, 2006b), and comes with a greater chance of age-related infertility, and consequently higher demand for ART (de Graaff, Land, Kessels, & Evers, 2011). Women in the support group had more opportunities for education and career than their mothers.

### **10.2.2 Expectations of ART**

People perceive having children as a fundamental aspect of life's journey, and the research queries if women had these expectations. The expectations and definitions of normal patterns of reproduction have changed, and women are more likely to seek medical intervention if they cannot get pregnant; they are also more likely to consider medical intervention as a standard procedure (Karpf, 1988). Many in the support and the interview group initially had expectations that medical technology would result in a baby.

Notwithstanding their outcomes from ART, only a quarter of the support group believed women aged 35 and older were likely to get pregnant using ART, compared to the general community who thought half of such a group would conceive. Half of all women in the community thought women aged 35 and older likely to conceive via ART. Around half the support group were unsure if a pregnancy or a live birth was likely or unlikely, indicating a lack of confidence in answering the question or a lack of knowledge enabling an answer. The community had double the expectation that ART will result in conception compared to women who had used ART. Women are likely to have modified their expectations they held before treatment, after having ART. In our society women may approach ART, or delay their childbearing, with the false belief that they have a good chance of a birth.

Nearly two-thirds in the support group gained fuller awareness of the facts and success rates of ART after seeking assistance from an infertility specialist. Women in MacDougall's study (2013) were highly educated but were not appropriately aware of age-related

infertility and had “age shock”. They were shocked to find that their knowledge of the period of fertility decline was incorrect, which had consequences for their decisions regarding pregnancy. Some interview participants responded that they were not given realistic indications of their chance of a live birth, which suggests a dichotomy between information provided by the clinic and what information is understood and retained.

Following on from beliefs of a pregnancy, subjects were asked if they believed an ART-conceived pregnancy would proceed to a healthy baby. This question intends to determine the knowledge of miscarriage rates especially among older females. Responses were similar to the likelihood of pregnancy as discussed above, with one-third of the support group believing in the high chance of a live birth compared to two-thirds of the community. Community’s expectations were higher, regardless of age group or gender, indicating inflated faith in this technology. Women should not consider ART as a fall back option or they risk unintentional childlessness (Weston & Qu, 2005).

Expectations of pregnancy may change once women engage with treatment and their hopes of success can be tempered. As one woman said “the expectations are incredibly different to when I started to what they are now”. Some women expressed the prevailing opinion that “you just went to a fertility specialist and walked out pregnant a few months later”. The support group was asked if they were confident that they would conceive before they started ART, and most women were sure of a pregnancy. Younger women were more confident of success than those aged 40 and older. Peddie’s et al (2005) research participants also felt they had commenced treatment with unrealistic expectations of success and required improved psychological assistance if their expectations were not met. Such unrealistic expectations may be prevalent, in part, as the procedures are described as routine and the risks of failure of the technology are downplayed (Sharp, 2000).

Expectations of success are also dependent on an understanding of medical impediments to conception such as advancing biological age. Maheshwari et al. (2007) demonstrated that 85% of their study’s infertile group expected ART to overcome the effects of their age-related infertility. Expectations can be shaped from women’s sources of information about ART. The support group suggested that their gynaecologist or obstetrician was a source of information on ART and its capacity to achieve pregnancy. Self-education on fertility and ART through sources such as newspapers, magazines, and the Internet was most influential for the support group. However, non-peer reviewed information on the Internet

can be misleading. Dougherty and Stovall (2010), for instance, found most women in the USA accessing the Internet for information before their first consultation had a significant misunderstanding of the number of clinic visits they may require and cost of treatment.

Most support group participants aged younger than 40 years perceived that clinicians gave them confidence that they had a good chance of pregnancy, and most felt the risks and options were clearly outlined. Physician optimism may result in underestimation of the risks and costs, and women may undergo invasive procedures that have little chance of success. Clinicians should ensure that complicated information on risks and treatment options are understood; Mourad (2009) suggests that as many patients perceive treatment as positive and a solution to their problem and may ignore warnings or negative information on the treatment. Some participants suggested the myth that women 'can have it all' indicated that family, career, and relationships were all possible. Sauer (2015) suggests this myth be condemned and women should not delay their childbearing until a convenient time.

Overall, women felt they were not pressured into deciding to use ART and were more influenced in making the decision to seek treatment from their primary health provider or relationship partner. Bronfenbrenner and Qu (1994; Qu & Weston, 2005) suggest that individuals in a relationship with close proximity most influence decision-making. Data did not totally support Bronfenbrenner's theory, as individuals close to women such as family and friends, were suggested as influences for less than half of the group. Public health information, including that shared by clinicians, was a source for three-quarters of the women. A primary health provider did not provide information for one woman who expressed regret that her family doctor of 20 years had never mentioned her declining fertility, and she suggested: "no-one talks about it." Findings suggest that the primary health provider should be a mindful source of information on fertility, infertility, and ART (Mazza, Cannold, Nagle, McKay, & Brijnath, 2012). Health resources from the Internet vary significantly in quality and accuracy, and patients need guidance from their clinician on evaluating accurate sources (Fahy et al., 2014). However, sourcing information from the Internet may place tension between the patient and their doctor (Henwood, Wyatt, Hart, & Smith, 2003). The choices women make on the timing of childbearing are only as good as the information provided to, or sourced by them.

Most of the support group had expectations that ART was the only way for them to have a baby and initially believed they would conceive after a minimal number of cycles. After

treatment, the majority of this group agreed that their current expectations of ART had been met and that their expectations were now realistic. They had tempered their expectations, as they were now aware of the limitations of the technology. It was also apparent after using ART that it did not allow women to ameliorate the consequences of delayed childbearing. Two-thirds of the support group were mindful of the fact that their fertility declined from the age of 35 years, and half the women were aware that oocyte quality could limit their chances of success. It is likely they garnered this level of knowledge from their infertility specialists, but that cannot be determined from the data. Potential users of ART may commence with unrealistic and uninformed expectations.

Many women seeking treatment mostly believed their decision to use ART was not hard to make and were clear that they had made a good choice. Findings also show that they were aware, at this point in their treatment, of their choices as well as the risks and benefits of ART. Having a child was not a life focus for most of these women earlier in their lives. Impediments to risk-taking and decision-making involve not only medical or scientific factors but also cultural, economic and political influences (Becker & Nachtigall, 1994). A laypersons perception of risk differs from those of health professionals, and may vary between different segments of the community due to individual priorities (Williams & Calnan, 1996a). Women were aware of the risks of ART, however this understanding may be more fully realised after stopping treatment.

It is possible that some women have unrealistic expectations of the success of ART, as the potential for the technology to fail to deliver a live birth are downplayed (Sharp, 2000). Data shows that some women initially had hopes which exceeded the reality of success. Richard Kennedy of the British Fertility Society stated: “there is an incredible amount of false and unreasonable expectation about fertility treatment and what it can do.” Further, that “doctors are partly to blame because of the way in which IVF is talked about”. He suggested that stories in the media about older and even post-menopausal women giving birth contributed to this increase in expectations (Firth, 2005).

### **10.2.3 Social issues around ART and timing of childbearing**

Western women are perceived to have considerable control over events in their lives. However, social factors that influence childbearing decisions may be difficult to manage. An understanding of fertility decline and timing of childbearing can originate from social connections. As an extension of Bronfenbrenner’s framework, individuals close to women are often influential with childbearing decisions and treatment (Bronfenbrenner, 1972,

1994). This research showed that the media and medical practitioners had a greater influence than family and friends on childbearing decisions.

The primary reason the support group selected for delaying childbearing was lack of a relationship partner. Career or work, financial security, education, and health issues were less significant. Some in the support group may have been able, when younger, to conceive spontaneously, however they did not have a supporting relationship partner. Two-thirds of the support group selected lack of a partner as the primary reason compared to just 4% of community members, particularly those aged 40 years or age or older. Interviewees noted that they “hadn’t found anyone worth having children with” or they simply did not meet a suitable partner. Holton (2011a; Holton et al., 2011b) suggests that health is a major issue for women delaying childbearing for women aged 35 years of age. However, only a small number of the support group thought health was a factor in women having children after the age of 35. Lack of relationship stability, multiple partners, and partnering relationships later in life are shown to influence women considering motherhood later in their reproductive life (Australian Bureau of Statistics, 2003a; Birrell, 2004; Gray et al., 2008; Weston et al., 2001). However, an acknowledgement must be made to the unknown complex social forces that shape the environment for decisions on timing of childbearing.

This study supports the work of Cannold (2000 ) who found, while interviewing Australian and North American women on their reasons for childlessness, that lack of relationship partner was the primary reason for women to be childless or to have fewer children than they aspired to have. A Canadian study found independence and a stable relationship influenced women’s fertility intentions, with the readiness of the partner to have children with lesser determinant in decision-making (Benzies et al., 2006). These findings were at odds with the responses of the community members in this study who perceive delayed childbearing as due mostly to career or work commitments.

Indeed, for some women they believed there existed an expectation for women to work until their mid-thirties and then consider pregnancy, and there was a desire for women to work and to “make yourself powerful and break the glass ceiling.” This type of perception was evident even among the younger members of the community. The public perception of women pursuing careers ahead of childbearing is not supported by data from the IVF support group whose circumstances have lead to the need for ART.



The general community, particularly those aged 40 years and older, noted that women also wanted financial security before having children, which was not strongly supported by the support group. One woman who had used ART agreed that for women at 40 years of age “financially it’s a better time.” Qu (2000) argues that the high economic cost of raising children also contributes to Australian women delaying childbearing.

Childlessness can leave women with a feeling of social isolation and alienation when their family and friends have children. Most in the support group found holidays and celebrations difficult, and felt left out when they saw families with children as supported by Kirkman’s research (Kirkman, 2001b). Women with involuntary childlessness can experience a lack of social support and life-long grief (Ferland & Caron, 2013). Qualitative data supported feelings of exclusion, as some women were reluctant to discuss their fertility issues with family and friends. Baker (2003) concludes that social exclusion due to childlessness made some people feel excluded from normal adult life while childless women may have less life satisfaction than women with children (Callan & Hennessey, 1988). Some support group members reflected on their feelings of isolation; Redshaw et al. (2007) recommend that health professionals should look at the individual’s experience of ART as many women found diagnosis and treatment an isolating and depersonalised experience.

Despite the availability of ART and social oocyte freezing, there are no guarantees these will avail women of a child. As a medical procedure, they pose a potential risk to mother and baby.

#### **10.2.4 Experiences of ART**

ART places physical and emotional stress on many women which has been widely documented in literature (Benyamini, Gozlan, & Kokai, 2005; Kopitzke & Wilson, 2000). The experience of ART for each woman will be an individual one, based on their history, expectations of the treatment, and outcome. Most women in the support group who had conceived believed the clinic offered them adequate emotional support during their treatment and looked back more positively on the experience. Women felt their clinician and clinic offered them treatment options and explained the IVF procedures.

Literature supports the findings that a caring and supportive clinic makes the experience of ART less severe than it otherwise would be (Hammarberg et al., 2001; Malin, Hemminki, Raikkonen, Sihvo, & Perala, 2001; Parry, 2004; Peddie et al., 2005; Redshaw et al., 2007).

Most in the support group found their ART experience difficult, and it would be expected that women who had a baby found the experience less stressful, or forgot how challenging the experience was for them. This finding aligns with Malin's et al. (2001) study showed women who were successful after ART exhibit a higher degree of satisfaction than women who do not.

The experience of ART was difficult for the majority of women over age 35 years, particularly for women aged 40 and older. Women aged 44 and older have only a 1:100 chance of a live birth (Lotz, 2012). This older group was less confident they would conceive again and gave a negative response when asked if that they would delay childbearing if given the choice. They also had the strongest belief that women delayed childbearing due to relationship issues.

Half of women in the support group agreed that the clinic offered them emotional and psychological support. Alesi (2005) suggests that psychological acceptance and resolution of the emotional roller coaster of ART may not occur until conception or treatment end. Psychological support and a sympathetic approach from the infertility clinic can make ART treatment easier for women (Malin et al., 2001). Women who are well-supported psychologically in the early stages of treatment and who are informed of the stress they may experience if their treatment is unsuccessful may be able to control these negative emotions (Hammarberg et al., 2001).

This study found there were taboos and secrecy associated with undertaking ART, for some participants and women were not always supportive of each other. Although ART is becoming accepted as a standard medical procedure, some women are secretive about using ART even in neutral research settings (Van Balen & Inhorn, 2002), .."it's like to them a taboo subject." One woman participant dispelled the notion that those undertaking ART would be fully supportive of each other, and suggested it is like a secret fraternity, .."if you walk into a clinic and you see ten other couples, not one of those couples will talk to you. I don't think it's shame, I think it's that's people are afraid of the success of others in my opinion." Zoll (2013) suggests that taboos are reinforced by infertility clinics that do not wish patients to discuss their infertility or the failure of ART; this absence of truth-telling may make success stories in the media even more misleading.

Some women in the study chose not to openly discuss their decision to use ART with family or friends: "I think there is a bit of a taboo, people don't want to talk about it with their friends or with their family and certainly wouldn't want to participate in something like

this because they might as well talk about things that are personal”. Research shows that couples pregnant after ART feel different from their fertile peers and are reluctant to share their excitement or concerns with their infertile friends of clinic support group for fear of hurting them or appearing insensitive (Glazer, 1998).

The hope of success in the next treatment cycle can make the decision to discontinue treatment a difficult step. Making the decision to stop treatment without having a baby forces some women to come to terms with their unresolved infertility and involuntary childlessness. However, it may help to relieve them of the emotional stress associated with ART (Peddie et al., 2005). One woman said “...I want to reach a point where I say you’ve got to let go...”. The ever-growing number of medical treatments offered by infertility clinics can pressure women to keep trying (Greil, 1991b). Treatment costs were not a factor in women stopping treatment. However, it was a limiting factor in the number of IVF cycles women could undertake.

Women were divided about whether the clinic had given them adequate support when deciding to stop treatment. Some clinics may be unaware of women stopping treatment as some may have long breaks between cycles, and are unable to offer timely support, as they are unaware that ceasing treatment is being considered. Ending ART moves women from hoping for a child to a childless state and women may require social support to develop new life goals (Verhaak, Smeenk, Evers, & Kremer, 2007). Women can be unprepared for making that decision and for recognising when that point has come: “I want to sort of reach a point where I say, okay, you’ve got to let it go and I sort of want to get on.” Peddie et al. (2005) found women were unprepared for making that heart-wrenching decision and wished a timeframe for stopping ART had been initially discussed with them. Women who are overwhelmed with their desire for a child can have a limited capacity to make that final decision (Rauprich, Berns, & Vollman, 2011). One participant reflected that “I feel it can also become quite an addictive treatment...maybe this next cycle will be the one”. Individuals may not be able to move to acceptance and resolution until there is a definite end to their ART experience by either having a baby or stopping treatment (Alesi, 2005).

Social and financial factors can be the catalyst in stopping treatment. Stress on partnering relationships may also be a trigger: “Emotionally and relationship wise it was taking its toll...we got to a point when we were almost having a separation”. Psychological stress is

attributed to the majority of couples who discontinue ART without a child (Olivius, Friden, Borg, & Bergh, 2004).

ART can either be a positive or a negative experience. For many women the ART experience is hard, emotionally and financially demanding, and for some women their experiences at the clinic impact on their decision to end treatment (Peddie et al., 2005). Women undertaking ART can experience anticipated decision regret where they are reluctant to stop in case their next cycle is successful. In this study, women who conceived suggested they wanted to avoid decision regret, whereas the women who did not conceive did not support this. In the event of infertility, women who wish to avoid regret about their decision to pursue ART may be motivated to make decisions which will lessen their chance of regret that they had not taken every opportunity available (O'Connor, et al 1999; Zoeten M.J et al 1987). In this study, two-thirds of women tried ART to ensure they had done everything possible to have a child which correlates with Tymstra's and others (de Zoeten et al., 1987; Tufan & Durmusoglu, 2004; Tymstra, 1989; Zeelenberg, 1999) discussion on the theory of anticipated regret. Stopping ART without a child involves the loss of a parenthood experience, loss of conceiving a child with one's partner, and the loss of the continuation of a family history (Cooper & Glazer, 1998).

A person may feel regret when the realisation that good outcomes of a certain decision are no longer possible before those consequences are experienced (Connolly, Edelman, & Cooke, 1992; Zeelenberg, 1999). Currently, there are no limitations on the number of ART cycles undertaken by women in Australia and the decision to stop treatment must be owned entirely by the individual. This study found the cost of treatment could restrict the number of cycles undertaken for some couples. Legislation to limit the number of Medicare-funded cycles available to older women is a recommendation of this research.

#### **10.2.5 Community attitudes towards ART**

Attitudes to ART will arise, in part, from knowledge and understanding of fertility and infertility. There was a lack of awareness about women's age-related fertility decline among some members of the community group in this study, with males showing less accurate knowledge compared to females. Daniluk and Koert (2015) suggest that as men have a longer fertility lifespan they are less aware of fertility issues.

The general community unrealistically had high expectations of a pregnancy and a live birth after ART. This was also apparent when comparing women who had used ART and

women in the community group. Hammarberg's (2013) community survey confirmed that Australian men and women have varying assumptions of the age of fertility decline. Wajcman (2004) showed that men and women have different perceptions of technology.

Community attitudes towards infertile married couples using ART have been surveyed; 77% of Australians surveyed between 1981 and 1994 supported the use of IVF by infertile couples (Cohen et al., 2005). By 2001, community approval increased to 86% (Kovacs et al., 2003), and to 91% in 2011 (Kovacs, Morgan, Levine, & McCrann, 2012). An Australian infertility clinic commissioned this survey. Questions were limited, and the responses interpreted favourably towards the infertility clinic to show widespread approval of ART and Medicare funding of ART. However, no success rates or treatment costs or cycle information was supplied to participants. Women are more influenced in their childbearing decisions by physical and emotional factors, and men more by economic factors (Newman, 2004). The community seems to support ART, but they have elevated expectations of the success rate of this technology.

#### **10.2.6 Medicalisation, marketing, and commodification of ART**

One research question proposed that women might have unrealistic expectations of the success of ART. Findings support this, and align with previous Australian research (as discussed in Chapter 1). The question regarding age-related infertility due to social factors is medicalised and that ART has become commodified is also supported by the findings. These show that many in the community sample had an understanding of age-related infertility which overestimates the age of fertility decline and the success of ART, perhaps influenced by media and marketing

Women attending an ART clinic are not ill; they are not able to conceive. Whether this is due to a biological impediment or age-related infertility, they require medical resources. As Sandelowski et al. (1990) intimates, infertility becomes an illness only by the virtue of one symptom that is the lack of a desired child. The question arises whether ART is a medical necessity and could be treated with less invasive and less expensive technology (Mladovsky & Sorenson, 2010) taking into account that there is a question as to the efficacy of ART for older women.

Within the context of a medical condition, the IVF support group felt the infertility clinic informed them about ART, options for treatment and risks of treatment. The expectations of women instigating and accepting ART treatment depends on an individual's beliefs

(Kamphuis et al., 2014). Australians have a high level of trust in science and consequently new technologies (Farquharson & Critchley, 2004). Women can trust an infertility clinic due to its reputation or marketing perception, which gives them the expectation that an infertility clinic has the processes in place to perform its tasks in a predictable and particular way (Farquharson & Critchley, 2004). This may have impacted on the acceptance of the clinic by some women in this study.

For some women who had used ART, this trust was tested when the clinician or clinic inappropriately elevated hopes of pregnancy by providing them with unrealistic expectations of success particularly in the early stages of treatment. This was illustrated when one woman's clinician told her "that all would be OK and I was given the impression that all would be quite easy" and the participant who was not pregnant after 17 cycles was "under the impression that we were going to be pregnant rather quickly." This research shows that some women were given the impression by infertility clinics that ART was very successful. Heitman (1999) suggests that infertile couples are vulnerable to the technology's seductive promises of parenthood. Most service providers over-estimate the success rate of ART (Hammer Burns, 1999; Peddie et al., 2005).

Commodification occurs when a medical procedure generates an item for sale. This may be evident for women when they are given inappropriate success rates and then sold ART - which comes with an uncertain outcome. In this study, one woman who had 12 unsuccessful cycles was told when she first attended the clinic that she was "given enormous odds, positive odds over 90%". Their clinician had assured most support group participants that they had a high likelihood of a conception, but not as frequently for women aged 40 and older. This study reveals clinicians encouraged half the women younger than age 40 years to continue treatment when they were unsure if they wished to stop, which delayed their decision to discontinue ART treatment.

Marketing by infertility clinics of the cumulative success rate rather than a live birth rate for each cycle is likely to be confusing to non-experts; it gives the impression of a higher success rate. One woman expressed her confusion: "I think it was a 95% success rate that they were going to get you pregnant in within a certain number of cycles - that's all I caught on to and that's all I believed in". Daya (Daya, 2005) suggests that the use of cumulative success rates for ART is not appropriate due to the passage of time and lack of informative censoring which may lead to an overestimation of the success rate and biased decision-making. In order to give better and comparable information between clinics,

Recommendation 10 in the Independent Review of ART in 2006, which was approved by the Department of Health and Aging, asks that clinics provide standardised outcome measures with the primary outcome presented being the live birth rate per initiated cycle (Department of Health and Aging, 2006); which has not been implemented by clinics. It is postulated that this may not been executed by some clinics as the real success rates would not be as favourable. Women cannot make informed decisions on the success of ART if success rates published by infertility clinics are overestimated. Promotion of pregnancy rates data rather than live birth rates is misleading, as not all pregnancies will proceed to term (Napoli, 1999).

Findings showed that over three-quarters of the support and community group felt that ART was portrayed in the media as a successful way for older women to have a child. The media often depicts misleading stereotypes of health conditions (King et al., 2014), so women may have false assurances based on the impact of the press and marketing of ART and make decisions on childbearing based on this premise. Lupton (2005) suggests that the media can overdramatise or simplify health issues that may distort understanding of them. There was little difference in attitudes in the community, between age groups or gender, in support of media influence. The implication of this finding is that the community, with their lowered awareness and knowledge of infertility and ART, believe that ART is successful for older women and be influenced by the positive media depiction.

The mass media has been shown to influence beliefs and perceptions and to manipulate public opinion (Kotler & Zaltman, 1971; Williams & Calnan, 1996a). It can portray ART as a standard medical procedure and give a positive view, which could encourage women to use ART. This reassurance of success may influence women to postpone their childbearing, especially as women in this study felt that the depiction of ART in the media was accurate, and the marketing of infertility clinics through the press is increasingly used to influence the public perceptions of medical technology (Karpf, 1988). It appears from the data that some older women who have engaged with the technology believed the success stories of IVF in the media, and had delayed childbearing with the belief that ART would enable them to have a baby. Unfortunately, the live birth rates for older women as shown in the literature do not support this assumption.

Published stories about women's experiences with infertility through television, women's magazines and newspapers are readily accessible. The Internet has become a reference source and a supporting body for women as blogs help to renegotiate women's

experiences when motherhood is hard to achieve (Harrison, 2014). Some women in this study felt that media stories were not an accurate representation of the experiences of the majority of midlife intending mothers who access ART.

A review of Canadian media showed nearly half of the stories mentioned positive outcomes (King et al., 2014). Stories in the media of miracle babies do not relate to the experiences of women who do conceive after using ART as one support group participant stated: “the publicity on IVF never shows the failure associated with it.” Several women said the depiction of older female celebrities as pregnant or with babies as ‘sensational’ and gave authority to the premise that pregnancy is achievable for older women. However, disclosure of such pregnancies lacks disclosure if donor gametes, donor embryos, or if autologous oocytes were required. One woman summarised the feeling of many women: “If I hear one more story about these 40 something celebrity’s having babies “naturally” I will scream.” Stories of miracle births for older women have contributed to an increase in expectations of success (Firth, 2005) for young women looking towards celebrities who are older parents (Kimberley-Smith 2003).

The history of the development of the ART industry shows a change from small business models that were clinician based, to clinics owned by venture capital companies. These acquire smaller Australian and international infertility clinics and tend to dominate the infertility market. Shareholders of ASX listed companies expect a dividend for their investment, as businesses need to grow and make a profit. Some women interviewed felt that they were part of a moneymaking business. It would be disappointing if those large companies used unsubstantiated information to market ART success rates and new procedures for profit.

It was anticipated that women would reflect more overtly on the business model of ART and commodification of infertility services and treatment. Few comments in this area were noted; it may be that, only after disengaging completely from ART and association with a support group, can women adequately reflect and analyse their experience. It is also possible that only the most highly educated participants consider this type of critical reflection.

### **10.2.7 Public health and policy implications**

Australia’s centrally-funded healthcare system, Medicare, provides financial assistance for eligible Australian citizens for services registered for treatment by registered medical and



allied health professionals. Many factors that influence childbearing are regulated by government policy (Gray et al., 2008). Some of these policies include childcare access, financial support, and birth and financial bonuses.

Policy discussions have focused on workforce participation and economic incentives to stem fertility decline. Within the Australian healthcare system, there is a constant struggle of justification as to distribution of available funds. Australia's aging population will require increasing medical services for conditions such as cardiovascular disease and joint replacement surgery. Health spending comprises one of the largest components of government expenditure and justification for the allocation of funds is in the public interest. Within the context of limited healthcare resources, the cost-effectiveness of ART needs to be justified.

ART is available via only privately owned clinics with high overheads and expensive fee structures. Mladovsky (2010) suggests that cost-effectiveness needs to take into consideration whether the outcome is focussed on quality or quantity. Based on the desires of women undertaking ART, the desired outcome is for a singleton pregnancy and a healthy mother and baby circumventing the need for expensive and challenging neonatal care (Schieve & Reynolds, 2004).

Medical conditions such as infertility can be socially constructed in that, rather than looking at the medical environment of the time, women are individually focused on their own circumstance. Policy issues need to consider the underlying social problems and complexities of women in their childbearing years and to understand there are no quick fixes for these complex challenges (Conrad & Barker, 2010). Social stigma towards involuntary childlessness and taboos towards infertility are a public health issue to note (Lemoine & Ravitsky, 2013).

The public funding of ART by Medicare has a policy history of a continual challenge from pressure groups, either medical or consumer, who have vested interests in the outcome. Public funding for ART will most likely steadily increase for two reasons. Firstly, women are having children later in life and consequently may require ART, as they cannot conceive naturally. Secondly, ART is becoming acceptable as a way to have children and public funding for ART is expected (Shannon, 2013). However, there are no controls about the potential inequity regarding who can claim a rebate from Medicare services. Women aged 40 years and older likely to be more financially secure than younger women as they have been in the workforce for longer. Unlimited and non-means tested ART cycles are

available to all women aged 40 and older and these women have the lowest success rates. Younger or less affluent women have reduced access to ART if they are unable to fund the out-of-pocket component of cycle costs (Lotz, 2012). Public policy needs to reflect changes in community and childbearing intentions of women. Consideration should be made to limiting the number of Medicare-funded autologous cycles available for women aged 40 years and older due to their diminished chance of a live birth compared to younger women (Macaldowie et al., 2014). This is supported by findings of this study in which older women, even knowing their slight chance of success, struggle to make the decision to stop ART. Once the funded cycle limit is reached for women aged over 40 years of age or older, it is recommended that treatment costs should be funded entirely by the patient.

Australia's protocol for single-embryo transfer has reduced the rate of multiple births, as multiple births have increased risks for mother and child as discussed in Chapter 4. However, this is not the situation in overseas countries such as the USA, where ART is self-funded or paid through health insurance. Consequently, the USA has a high rate of multiple births (26.6%) as women try to maximise the chance of a conception by multiple embryo transfers (Centers for Disease Control, 2013). Australia's multiple birth-rate in 2013 for ART-conceived pregnancies was 5.6% (Macaldowie et al., 2015). Australia's funding and regulation of ART is unique compared to other countries in the developed world.

Overall, women who used ART did not gain knowledge on fertility and ART from an educational institution such as a school or tertiary institution. The potential exists for many people without access to reliable and accurate information to trust their clinician for information (Kahlor & Mackert, 2009). Henwood et al.(2003) found the search strategies of consumers were dependent on their ability to access accurate information with some constraints due to the patient's requests for information from their GP being dismissed or rejected. Information may not be sourced from a GP and an easily accessible source of information is provided by infertility clinic marketing campaigns, which have not been demonstrated to give an entirely accurate portrayal of ART (Chan, Schon, O'Neill, & Masson, 2014). Hammarberg and Clarke (2005) suggest that women may resent not being informed of age-related fertility decline and scientists, journalists and primary health providers need to ensure that this information is in the public domain. Accurate and easily accessible information could be provided through the Royal College of General

Practitioners in Australia, circumventing the need for GPs or other primary health providers to rely on infertility clinics to provide such information.

Analysis shows there to be three groups of women highlighted in this research. Firstly, there are women who believe they are informed but they may not be (including many in the general community); secondly, there are those who are not informed and who become aware of risks along the treatment journey. Thirdly there are those who are informed but choose to delay childbearing anyway (Cooke, 2010). Pre-conception education could assist the first two groups, and the third group could make a more fully informed choice. Governments have the power to initiate a preventive health approach focused on young adults in educational facilities (Lemoine & Ravitsky, 2013). Government funding could be made available to encourage couples to develop a reproductive life plan with their GP, family planning clinic, or gynaecologist to assist development of a timeline for childbearing. Health professionals need to provide easily accessible and accurate information on reliable websites to provide unbiased information; this may help to avoid involuntary childlessness (O'Connor & Johnson, 2005). Specific information from ART clinicians is required for effective decision-making on commencement, treatment options, and decisions to end treatment if necessary (Mounce, 2013).

Lupton (2005) suggests that individuals have the option to avoid lifestyle risk behaviour. Ignoring information about risks to health places the individual in danger of illness or disability and to incur costs to the tax funded medical system. Extrapolating this to women who are aware of age-related fertility decline and delay childbearing for social reasons. This places their health and the health of a future baby at risk and adds to the demands on the taxpayer funded health system. Guidelines and predictive models should be developed to ascertain if women unable to conceive after 12 months should initiate ART at that stage or if, recommendations to continue trying for a spontaneous conception for a period should be implemented as it would be preferable if younger women did not have to undertake medical intervention if possible (Herbert et al., 2012; McLernon, te Velde, Steyerberg, Mol, & Bhattacharya). In the case of intentionally delaying childbearing, questions arise whether treatment should be publically or self-funded if treatment is due to social or lifestyle factors (2006).

Bronfenbrenner's (1977, 2005) theories surrounding social ecology propose that there are multiple layers of factors which influence health behaviour. Women were influenced by their beliefs on the age of childbearing and success of ART by people close to them such

as their partner, to more indirect influences such as media and marketing. Health information could be aimed at influences proximal to women making childbearing decisions. Mills et al (Mills et al., 2015) suggests health professionals and public policy needs to expand the current paradigm of advanced maternal age and childbearing

Government health policy aims to provide equitable health care, but this is a difficult balance to achieve as there is an insatiable need for services and technology which challenges government budgets (Haines, 2008). New policy initiatives that seek to reward fertility, such as financial bonuses for babies, will not be enough to encourage and support childbearing. Improvements to women's workplace options and accessible childcare are essential for women planning childbearing (Mahon et al., 2016). If governments are concerned about fertility levels, then policy should be coordinated across employment, health, education, and family services. Society needs to consider the impact our attitudes and expectations about parenting are having on women (Maher et al., 2004). Evaluating the cost-effectiveness of medical treatments is a challenge in medicine when health costs are rising and are one of the main areas of expense for many governments (Mastenbroek & Repping, 2014). Accurate information on costing of ART and success rates for women of all ages allows women to make an informed choice and potentially decrease the need for ART in the future.

### **10.3 Key Findings**

1. The clinical process of infertility treatment can be a stressful event. Social isolation and secrecy were evident.
2. Women in the support group were aware of age-related fertility decline. They felt that lack of a relationship partner was a key problem for timing of childbearing.
3. Women who had engaged with ART believed that lack of a relationship partner was the primary reason women delaying childbearing. The generally community believed that women focusing on career and work were the main reasons.
4. Community members, both males and females, have elevated expectations of the success of ART and perceive ART to be successful for women aged over 35 years. Women who used ART had more realistic expectations of the success of treatment once they started treatment.

5. Some women had high expectations of success and these were lowered once they started their treatment as they discovered they had less chance of success than they first believed.
6. Most participants perceived media portrayed ART as a successful way for women aged 35 years and older to have a baby. Some women were frustrated by an unrealistic media portrayal of older women and older celebrities having children later in life.
7. Several women felt discomfort with the level of the commodification of their ART experience.
8. Women wish to avoid decision regret which may occur if they stop treatment before they are successful. Those who had been unsuccessful struggled with the decision to stop treatment, particularly as some believed help was not available to them when they required counselling .
9. Recommendations from the support group to women in the community are discussed in Chapter 11.

#### **10.4 Significance of the Findings**

The study was important to voice the concerns of women who had experience of ART. For such a group, their ability to discuss their experiences with women in the community is limited. These findings are significant as they compare the beliefs of women who have used ART with views of the community who generally would not have previous experience. Findings indicate that the community has exaggerated expectations of the success of ART, incorrect opinions of the age when women's fertility declines, and false assumptions for women's reasons for delaying childbearing. Consequently, it is not surprising that women are delaying their childbearing and relying on ART as a fall-back option. They held similar opinions when they were making these life-altering decisions. This study has the advantage of examining views of women by an independent researcher who has no ties to infertility clinics.

The study's strengths lie in the mixed methods approach. Information obtained from surveys supplies statistical data to give an overview of the perceptions, expectations and attitudes of two major participant groups: women who have engaged with ART and the community who may not have had direct knowledge or engagement. However, it is the extended interview data which enrich and expand upon the quantitative data and which give greater insight into the lived experience of ART. These qualitative data are a powerful

reflection of women's engagement with ART. The research findings indicate a lack of knowledge of fertility decline and the danger of relying on ART as a fall-back option. Findings suggest the initiation of an educational programme for the general community and primary health providers. Findings provide an overview of ART at the current time which could be used as the basis for a larger or longitudinal study of ART.

### **10.5 Limitations**

This study has several limitations. The size of the study is a limitation, but the specificity of the study limited its size and the sampling strategy. As Patton suggests (2002: 120) all research contains some imperfections, personal judgements, limitation of resources, and creativity. Responses obtained from only 68 women in the support group represent a restriction of the research, and a larger cohort of women would have given a stronger statistical result (Button et al., 2013). Not all the questions were answered and responses from all participants would have strengthened the findings. However, this can be difficult without the full cooperation of an infertility clinic, which was not forthcoming in this study. However, trends certainly emerged from statistical analysis and were further explored in depth in the interviews and across the breadth of the community.

As Yusen and Littenberg (2005) note, selective sampling may enroll subjects with certain characteristics. This may result in sampling bias that leads to a non-representative sample of the population. Within the support group and the interview group, were women with varied experiences of ART and different reasons for using ART, which would reduce the selection bias of the sample. A larger sample size would help to eliminate the possibility of selection bias. The online survey findings raised some issues of concern which were explored in depth within the interviews. Responses from participants attending a cross-section of clinics would be enlightening, as the participants in this research may have had a better or worse experience than women attending other clinics. As participants were self-selected volunteers, they may possess certain characteristics that have the potential to impact upon the general nature of the findings.

As infertility is a private issue and emotionally challenging to discuss in the context of an investigative survey or interview, non-compliance is not unexpected (Van Balen, 2002). Many women found their experience with ART to be a painful emotional and physical experience that may have resulted in some women considering the research questions challenging. Clearly for women who had a successful outcome, they may be more comfortable to relating their experiences compared to women who were unsuccessful.

Kessels (2003) suggests participants have subjective perceptions and assessments that may impair recall of events. In this research, women's perceptions of their experiences and beliefs may be influenced by factors such as continued engagement with ART, length of treatment, and previous success. Personal views of ART experiences could be made clear upon reflection once disengaged from treatment or after some time embedded in the treatment experience; the length of time the members of the support group had undertaken treatment was not obtained. However, women in the support group had not completely removed themselves as many were supporting other women currently undergoing treatment.

Most of the support group women had at least one pregnancy and most had, at least, one live birth during their treatment time. Data does not indicate how many cycles these women undertook or stage of embryo transfers. This is a potential limitation, as the data was not able to be linked to clinical cycle records. It is well documented that after five cycles of ART, there is little chance of pregnancy regardless of a woman's age, and the sixth cycle only increases the chance by 0.7% (Macaldowie et al., 2013). Within the qualitative research group, some women had a baby but many women did not get pregnant after multiple cycles of ART, as shown by an interview participant who had completed 17 cycles of ART.

## **10.6 Directions for future research**

A robust analysis by an independent body should be conducted into the cost-effectiveness of ART. There is no limit on Medicare rebate for ART cycles, and as discussed, there is little likelihood of conception after five or six cycles. Research should be undertaken into whether a limitation in the funding level would encourage women to start childbearing earlier in life or to make easier the decision to end treatment. Currently, some analysis had been undertaken in this area; however, an infertility company financially supported the research and it cannot be deemed independent research.

Further research into the social reasons surrounding partnering relationships and women's childbearing decisions could be initiated on the basis of this study. This research could discuss with women who have delayed childbearing socially constructed reasons for this trend. Strategies are required to mitigate this trend or to inform females of age-related fertility limits and ART to counteract fertility decline. However, Dr. Jane Fisher suggested that since Australian clinics became commercial entities they are less supportive of psychosocial research (Cohen, 2015).

Further in-depth research on best practice in disseminating information to women and girls about their fertility could be undertaken. This would enable information on the actual success rate of ART for all age groups of women made available. Simplified information on the success rate per cycle pertaining to women's age for ART and PGD is recommended. This information needs to be gained from ANZARD rather than from individual clinics to provide some consistency and reliability to clinic marketing.

The quantitative aspect of the study could be repeated with a larger sample size to examine, with greater statistical power, relationships between the main variables. A longitudinal study of women's beliefs of ART and timing of childbearing would be very valuable. Further investigation could commence with young women and follow them over time during their childbearing years.

Further research into the understanding of the success rates of ART by primary health providers such as GP's, sexual health clinics, and gynaecologists is needed. Marketing information supplied by infertility clinics may be the only source of information for primary health providers and may impart an unrealistic view of ART. A survey of the knowledge of primary health providers and their sources of up to date information on ART would give an indication of deficiencies and strengths. If required, a strategy to improve the knowledge of these front line professionals could be implemented through the Australian Medical Association.

Clearly the concept of women struggling to make the decision to stop ART treatment is of concern and deserves further investigation. Findings support the theory of anticipated decision regret when women would continue treatment, even if there were a slim chance for pregnancy, as ART offered the only avenue to avoid regret

## **10.7 Summary**

The research questions explored women's expectations and experiences of ART, factors influencing the decision to delay childbearing, and the medicalisation and marketing of ART. A mixed methods approach was adopted to explore these questions. Several limitations to the research are acknowledged.

Findings indicate that lack of accurate knowledge of fertility, infertility, and its treatment are widespread in the community. Community expectations of the success of ART and the



reasons for women delaying pregnancy are not realistic. Media misrepresentation may influence this.

Women who had used ART were influenced when making decisions by IVF clinic marketing, sometimes their GP, and the media. Realistic expectations only developed over time and with experience. These women overwhelmingly reported lack of a partner as the key reason for delaying childbearing.

The emotional side of the unending desire to be a parent must be balanced against practicalities. This applies to women who have delayed childbearing for personal reasons with the intention that they can use ART if necessary. Delaying childbearing can only be considered as risk behaviour if women are aware of the decline in fertility related to maternal age. Some women have chosen to accept the risk in delaying childbearing. Delayed childbearing has a personal, financial and psychological cost for the woman, as well as society and public healthcare funding. Policy discussions have focused on workforce participation and economic incentives to stem the fertility decline; however, financial incentives cannot help women establishing partnering relationships that support families.

Although ART has assisted many women, there is no guarantee of a baby. Having children before fertility wanes increases women's chances of having a technology free conception, the number of children they aspire to have, and to avoid involuntary childlessness. Women can choose to have control over this part of their lives if they overcome social impediments to having children at the most opportune time.

## Chapter 11: Recommendations

Recommendations arising from this study are outlined below. Some women in the support group and the interview group were keen that their recommendations be acted upon to effectively educate younger women and to prevent others from suffering infertility as detailed in Chapter 9.3.12.

1. A coherent body of knowledge is required in the public domain to educate the community on success rates, physical and psychological challenges and the medical procedures of ART. A greater public awareness of age-related fertility should be implemented to the community and adolescents through school-based education programs. Knowledge of age-related fertility decline and limitations of ART can be improved in primary health providers such as GPs so they can inform their female patients of childbearing age. This information should be independent and accurate.
2. An independent regulator should monitor and censor information marketed to GPs, in the media, and from infertility clinics. The regulator should be managed by an Australian government body and should remain independent of agencies who have a vested commercial interest such as infertility clinics, pharmaceutical companies and support groups such as Access Australia.
3. Cumulative success rates need to be reviewed to avoid unrealistic expectations of ART success. More realistic success rates allowing a fair comparison between infertility clinics should be in the public domain. Publication of live birth rates per cycle for each age group is recommended by the Department of Health and Aging (Department of Health and Aging, 2006).
4. There is a need for a debate on the distribution of publically funded healthcare in ART. A discussion in the public domain should be initiated on the public funding for unlimited ART cycles, particularly when there is a very low success rate for women aged 40 years.
5. Less invasive techniques for treating infertility and the need to promote lower dose stimulation cycles should be encouraged to give women with simple solutions to the aetiology of their infertility the option of low-cost treatment.
6. Infertility clinics should provide women with realistic expectations of success before they start their first treatment cycle and free psychological counselling

for women who are struggling with treatment, have repeated failed cycles and who have difficulty stopping treatment.

7. Women who do not have a baby after ART and are ending treatment need to find new role models who can help them move ahead into a future life without children and infertility support groups can provide empathy and understanding. Not all women will seek help and need to be aware of the availability of specialised psychological counselling for themselves and their partner if required. At the end of fertility treatment support staff should be able to discuss the future with patients.
8. Public health information should be aimed at younger members of the community using technology such as social media and informed media sites.

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## Appendices

**Appendix 1**

**Survey B: Support group survey**



## Friends Support Group Survey

### 1. Women aged 35 and older: Their experiences, expectations and influences on ...

In Australia, there has been very little research into the experience of women attending an infertility clinic. An infertility clinic is a place that women attend with the expectation that they will probably take home a baby. For many women this will be the scenario, but not for all women. Information about women's experiences and expectations of seeking assistance for infertility through an infertility clinic are being explored through this survey and with interviews with some participants.

I am inviting you to participate in the survey as you are registered as a member of the Friends Support Group and are therefore likely to be a past, present or future patient of an infertility service. This survey research is not being done in conjunction with any particular infertility clinic however and your experiences and perceptions will remain confidential and anonymous confidential. As the survey is being facilitated through the Friend's email listing, I as the researcher will not know the identity of any people who complete the survey.

This research is being conducted as part of my Doctoral research, and aims to examine the experiences and expectations of Australian women attending an infertility clinic.

This research has the full ethical approval from CQUniversity Australia. If you have any questions about this research please contact the Central Queensland University Office of Research (Tel 0749232067) or the Principal Researcher, Andrea Hayward on 0428163031 or the Research Supervisor, Associate Professor Sandra Taylor on 0749306598. Participation in this questionnaire will not effect your treatment at the clinic. Your responses will be coded and anonymous and only available to the researcher and research supervisor.

To participate in this questionnaire please complete the online survey which should take approximately 10 to 15 minutes. Participation in the questionnaire is entirely voluntary, is anonymous and cannot affect any treatment you may receive from an infertility clinic. Your responses will be fully anonymous and will be coded and only available to the researcher and research supervisor.

Thank you for your time and support in completing this survey. I hope the research about women's experiences and expectations of infertility treatment will improve and enhance the experience for women using Assisted Reproductive Technology in Australian infertility clinics.

Please complete and submit your survey online by November 14th. Thank you.

### 2. Demographics

#### 1. What was your age at your last birthday?

Please enter you age

#### 2. What is your country of birth?

- Australia  
 Country other than Australia

#### 3. What is your mother's country of birth?

- Australia  
 Country other than Australia

## Friends Support Group Survey

### 4. My situation regarding infertility treatment is:

- I am currently undertaking infertility treatment  
 I have undertaken infertility treatment in the past 12 months  
 I have undertaken infertility treatment in the past 2-3 years  
 I have undertaken infertility treatment more than 3 years ago  
 I am intending to undertake infertility treatment within the near future

Other (please specify)

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### 5. Please describe from the list below, your current personal relationship at the time of the infertility treatment and the length of time of that relationship?

	Yes	Yes	No	Same sex	less than 1 year	1 to 5 years	Longer than 5 years	Not applicable
Married or partnered	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Separated or divorced or widowed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Single and never married or had a long term partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Single after a long term relationship	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other (please specify)

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### 6. Are you still in that same relationship now as when you were undertaking fertility treatment?

- Yes  
 No  
 Still having infertility treatment  
 I have not started infertility treatment yet

Other (please specify)

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### 7. What is the highest level of education that YOU have reached. One tick only please.

- High school to grade 10  
 High school to Grade 12  
 Trade qualification or apprenticeship  
 Certificate or diploma  
 Bachelor's degree (including Honours)  
 Postgraduate degree

## Friends Support Group Survey

**8. At the present time, which best describes the activity that constitutes at least 20 hours per week of YOUR time each week. One tick only please**

- Working full time for pay
- Working part-time or casual for pay
- Unemployed and looking for work
- Student
- Household duties
- Carer for a family member
- Unemployed
- Retired from paid work
- Volunteer worker
- Other

**9. What is the highest level of education that your MOTHER has reached. One tick only please.**

- High school to grade 10
- High school to Grade 12
- Trade qualification or apprenticeship
- Certificate or diploma
- Bachelor's degree (including Honours
- Postgraduate degree or diploma

**10. Which of the following options best describes the activity which constituted at least 20 hours per week of your MOTHER'S time during your childhood. One tick only please**

- Working full time for pay
- Working part-time or casual for pay
- Unemployed and looking for work
- Student
- Household duties
- Carer for a family member
- Unemployed
- Retired from paid work
- Volunteer worker
- Other

## Friends Support Group Survey

### 11. What age was your mother when she had her first child?

- younger than 20 years
- 21-30
- 31-39
- older than 40
- Don't know

## 3. Fertility Story

### 12. Have you ever had a pregnancy without using Assisted Reproductive Technology?

- Yes and a child born
  - Yes but pregnancy miscarried
  - No
  - Other
-

## Friends Support Group Survey

**13. The following statements relate to your beliefs about your fertility at Please select the answer which best reflects your beliefs about each statement**

	Strongly agree	Agree	Disagree	Strongly disagree	Unsure
I think I will achieve a pregnancy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My fertility doctor told me I had a good chance of a pregnancy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
After speaking to the fertility doctor my hopes of a pregnancy are increased	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This is the only way for me to have a baby	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have been trying to achieve a pregnancy for less than 1 year	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have been trying to achieve a pregnancy for more than 1 year	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have no partner and need to use donor sperm	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have a male partner and need to use donor sperm	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have a female partner and need to use donor sperm	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I need to use donor eggs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I need to use donor embryos	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I believe there is no problem with the quality of my eggs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I need to access IVF as I have endometriosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I need to access IVF as my partner has sperm quality problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Friends Support Group Survey

### 15. Looking back, what do you think have influenced towards your beliefs about Assisted Reproductive Technology, what it is able to achieve and its capacity to achieve a pregnancy

	Very strong Influence	Strong influence	Some influence	Has not influenced	No influence at all
Classes at school, university or college	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Self education	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Public health information	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family members	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Work associates	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gynaecologist/Obstetrician	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Newspapers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Women's magazines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Television programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Internet websites	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
General community knowledge	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify)	<input type="text"/>				

### 16. What do you believe is the MAIN reason that some women delay motherhood (having a baby) until a later age? Tick one only please

- Career/work reasons
- Furthering their education
- Lack of a partner
- Health issues
- Financial security
- Don't know

Other (please specify)

## 4. Infertility and the IVF experience

## Friends Support Group Survey

**17. At what age do you believe women's fertility, or chances of becoming pregnant, begins to significantly decline?**

- 25-29 years of age
- 30-34 years of age
- 35-39 years of age
- 40-44 years of age
- 45-59 years of age
- 50-54 years of age
- 55 years of age and over

**18. For this question, I will declare that medical research has shown that a woman's fertility begins to significantly decline at the age of 35.**

**Given this information, and using the following scale from of 1 to 10, where 1 is not at all likely and 10 is very likely, how likely do you believe women over the age of 35 are to fall pregnant using medical assisted reproductive technology such as in vitro fertilisation (IVF)?**

- Not at all likely
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- Very likely

## Friends Support Group Survey

**19. Using the same scale, how likely do you believe it is that women over the age of 35 who falls pregnant using IVF will go on to deliver a healthy baby?**

- Not at all likely
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- Very likely

**20. Do you believe that the media, including magazines and current affairs programs, portray IVF as being a highly successful way for older women to become pregnant?**

- Yes
- No
- Unsure

**21. If you had delayed childbearing until aged 35 or older, the following question asks you to reflect upon that decision by indication which answer best reflects your views**

	Strongly agree	Agree	Disagree	Strongly disagree	Not applicable
It was the right decision	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I regret the choice that was made	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I would go for the same choice if I had to do it over again	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The choice did me a lot of harm	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The decision was a wise one	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not applicable as aged under 35	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify)	<input type="text"/>				



## Friends Support Group Survey

**22. If you are currently undertaking infertility treatment the following question asks about possible limitations you may see in regards to using Assisted Reproductive Technology. One tick only please.**

- Yes time limitations
- Yes treatment costs
- Yes egg quality problems
- No
- Unsure
- Not having any more treatment

Other (please specify)

**23. If you are currently attending the infertility clinic, can you select what you envisage your chance is of having a baby?**

- 0 to 20 %
- 20 to 40%
- 40 to 60%
- 60 to 80%
- 80 to 100%

## Friends Support Group Survey

**24. The following questions look at some of the important decisions that you made about using Assisted Reproductive Technology before attending the clinic. Please answer the questions that best fit your view about in the following section and indicate with a tick in the appropriate box how you feel about each statement**

	Yes	No	Unsure
The decision is hard for me to make	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I'm not sure what to do in this decision	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It's clear what choice is best for me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I'm aware of the choices I have in reproductive technology	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel I know the benefits of reproductive technology	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel I know the risks of reproductive technology	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I need more advice and information about the choices	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel pressure from others in making this decision	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel I have the right amount of support from others in making this choice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel I have made an informed choice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The decision shows what is most important to me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I expect to stick with my decision	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am satisfied with my decision	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Friends Support Group Survey

**25. This question relates to when you were making the decision to attend the infertility clinic. Please answer the question as accurately as you can about how you felt at the time you were making your decision to use Assisted Reproductive Technology. Did the following individuals or organizations have a strong effect on your decision to contact the infertility clinic. Please tick one option only.**

	Yes	No	Unsure
Partner	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medical Practitioner	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Neighbors	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Media	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Religion	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community opinion	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Beliefs in technology and science	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

## Friends Support Group Survey

**26. For many people, issues around child-bearing and fertility are very important and can be quite emotional. This section is inquiring about some of the emotions you may have experienced in relation to questions about having children at the time you attended the infertility clinic. I am aware that some of these questions may be difficult to answer. Please reflect how you feel about these statements at the moment**

	Yes	No	Unsure
It doesn't bother me when I'm asked questions about children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family members don't seem to treat us any differently	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The holidays and celebrations are especially difficult for me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family get-togethers are especially difficult for me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I can't help comparing myself with friends who have children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have lots in common with friends who have children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I find it hard to spend times with friends who have young children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I see families with children I feel left out	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel like friends or family are leaving me behind	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It doesn't bother me when others talk about their children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Friends Support Group Survey

**27. This question asks you to reflect upon the beliefs that have influenced your decision to try to have a child now. Please chose your responses as they related to your personal decisions.**

- It is difficult for some women to find a partner to share family life with
- Having a child is a major focus in my life now
- Having children was not a major focus in my life 5 years ago
- I would have had children earlier in life but was not in relationship that supported children
- I would have had children earlier but I was pursuing an education
- I would have had children earlier but I was pursuing a career
- I would have had children earlier but I was waiting until I was financially security
- I felt I had to try IVF to feel that I had done everything possible to have a child

Other (please specify)

---

## Friends Support Group Survey

### 28. These questions are reflecting on your experiences at the infertility clinic.

	Yes	No	Unsure	Not applicable
The clinic offered adequate emotional support during treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My doctor explained the medical procedures in sufficient detail	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My doctor gave me all the possible treatment options	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My doctor influenced me to have treatment or to continue treatment even though I was unsure at the time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I felt out of control with the treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The treatment costs limited the number of treatment cycles	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The treatment options were adequately explained	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The risks of treatment were adequately explained	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information about drugs and possible side effects was adequately explained	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The psychological support offered by the clinic was adequate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The clinic offered support when deciding to stop treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I tried IVF so I would not regret I had tried all options	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify)	<input type="text"/>			

## Friends Support Group Survey

### 29. These questions are reflecting on your expectations and expectations of Assisted Reproductive Technology and the infertility clinic

	Yes	No	Unsure	Not applicable
My expectations of the technology were met	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My expectations of the technology were realistic	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My doctor understood my expectations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My expectations of a sympathetic service were met	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The experience was difficult	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The experience was not as difficult as I expected	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The experience was worth it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

---

### 30. These questions are inquiring about the outcomes of treatment at the clinic

	Yes	No	Unsure	Not applicable
As a result of treatment at the clinic I had at least one pregnancy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
As a result of treatment at the clinic I had a live birth	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had a pregnancy but it did not continue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am still trying for a pregnancy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I will keep trying until I have a child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have stopped attending the clinic and I have a child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have stopped attending the clinic and I do not have a child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

---

## Friends Support Group Survey

### 31. I have stopped treatment at the clinic due to:

	Yes	No	Unsure	Not applicable
I am pregnant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have a baby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have adopted a child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The emotional cost was too high	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The financial cost was too high	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have decided to move to a childfree life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The treatment placed stress on my personal relationships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I had had enough treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify)	<input type="text"/>			

### 5. Further comments

You may wish to write a story or add comments about your experiences with Assisted Reproductive Technology. Writing some comments about your experiences will give an insight into each woman's story.

You may choose to add your comments after completing the questionnaire.

### 32. Please add any further comments or your experiences of infertility treatment.

**Thank you**



# CSSR

*The Population Research Laboratory*

Queensland Social Survey 2008

Final Sampling Report

Prepared by  
Miss Christine Hanley and Professor Kerry Mummery  
Population Research Laboratory  
Centre for Social Science Research  
CQUniversity Australia  
September 2008



C:\*\*\*\*\*  
C: DECLINE IN FERTILITY AND IVF (A. Hayward - CQU/DNAQ)  
C:\*\*\*\*\*

Q: QAH1  
T: 5 10

The next few questions are about the issue of declining fertility in women. Please remember there are no right or wrong answers, we are simply seeking your opinion.

What do you believe is the MAIN reason that some women delay motherhood (having a baby) until a later age?

READ CATEGORIES 1-5

1. Career/work reasons
2. Furthering their education
3. Lack of a partner
4. Health issues
5. Financial security

DO NOT READ

6. Don't know/No response
7. Other (please specify)

I:

Num 1 7

If (ans<7) skip QAH2

Q: QAH1b

T: 5 10

Specify other

ENTER COMMENTS

I:

Opn

Q: QAH2

T: 5 10

At what age do you believe women's fertility, or chances of becoming pregnant, begins to significantly decline?

[Remember, we are simply seeking your opinions]

READ CATEGORIES 1-7 IF NECESSARY

1. 25-29 years of age
2. 30-34 years of age
3. 35-39 years of age
4. 40-44 years of age
5. 45-59 years of age
6. 50-54 years of age
7. 55 years of age and over

DO NOT READ

8. No response

I:

Num 1 8

Q: QAH3

T: 2 5

[READ STATEMENT BELOW]

Medical research has shown that a woman's fertility begins to significantly decline at the age of 35.

Given this information, on a scale of 1 to 10, where 1 is not at all likely and 10 is very likely, how likely do you believe women over the age of 35 are to fall pregnant using medical assisted reproductive technology such as in vitro fertilisation (IVF)?

1. Not at all likely
2. 2
3. 3
4. 4
5. 5
6. 6
7. 7
8. 8
9. 9
10. Very likely

DO NOT READ

11. No response

I:

Num 1 11

Q: QAH4

T: 5 10

Using the same scale, how likely do you believe it is that women over the age of 35 who fall pregnant using IVF will go on to deliver a healthy baby?

1. Not at all likely
2. 2
3. 3
4. 4
5. 5
6. 6
7. 7
8. 8
9. 9
10. Very likely

DO NOT READ

11. No response

I:

Num 1 11

Q: QAH5

T: 5 10

Do you believe that the media, including magazines and current affairs programs, portray IVF as being a highly successful way for older women to become pregnant?

1. Yes

2. No

DO NOT READ

3. Don't know

4. No response

I:

Num 1 4

**Appendix 3**

**Survey D: Interview questions**

## Interview Question outline

### **Project Title:**

Women aged 35 and older: Their expectations, experiences, and decisions regarding Assisted Reproductive Technology (ART)

### **Draft question outline**

- Please tell me who you are and where you are in your IVF journey .....
- What are your personal reasons for having a family at this stage of your life?
- What do you think about women looking to childbearing when aged 35 or older ?
- What is your understanding of when women's fertility starts to decline?
- How would you rate the chance for a women aged 35 or older to have a pregnancy through IVF in a range of 1 to 10 where 10 = most successful)?
- How would you rate the chance for a women aged 35 or older to have a live birth (in a range of 1 to 10 where 10 = most successful)?
- What perception do you think the media gives women of the success of IVF?
- Do you think media stories influence women's timing of childbearing?
- Do you think the marketing information supplied from infertility clinics shapes women's impression of IVF technology and success rates?

- Have your expectations of the IVF technology been met?
- What are/were your experiences of going through IVF treatment?  
Was that different to the expectation before you started IVF?
- What did you think the success rate of IVF was before you accessed the clinic?  
Has your perception changed now?
- Taking your experiences into account, do you have advice for other women about the best age to have a child?
- Do you think it is difficult for women to stop IVF cycles if they have not had a baby ?  
What factors could influence their decision to stop?

**Appendix 4**

**Participant consent forms and information sheets: Survey B**



Central Queensland  
UNIVERSITY

**Project title:**

**Women aged 38 and older: Their experiences, expectations and influences on decisions regarding Assisted Reproductive Technology for age-related infertility**

Researcher: Andrea Hayward, PhD student, School of Science, Engineering and Health, Central Queensland University

Research supervisor: Associate Professor Sandy Taylor, Head of the School of Science, Engineering and Health, Central Queensland University

To the research participant,

Thank you for agreeing to receive more information about this research project. This research is exploring women's reasons for attending an infertility clinic for treatment and the experiences these women have after 6 months of infertility treatment. There has been, in the Australian context, little research into women's experiences while undertaking Assisted Reproductive Technology. This research will also explore women's expectations of the technology and if their expectations were fulfilled. The research group will comprise women aged 38 and older who require Assisted Reproductive Technology to achieve a pregnancy.

The research data and the findings collated from this survey will form the basis of my doctoral research at Central Queensland University. Findings from the research may be used in a peer reviewed publication or in a conference paper. However, no information that may identify the participants' identity will be used. Women will be asked to participate in the research when registering to attend the infertility clinic. Participation will involve completing two questionnaires, one when you first attend the clinic, and one again 6 months later. Some women will also be invited to be interviewed for the study. Women who agree to participate, and complete the survey, will be asked to complete a similar survey 6 months after they completed the initial survey. Questionnaires can be returned in the enclosed stamped addressed envelopes.

Women who offer to be interviewed for the study, will be interviewed at a time and place of convenience to you. The interviews will be audio-taped and you will be offered an opportunity to see the transcript of your interview and make comments.

Involvement in the research is on a voluntary basis and refusal to participate in the study will not affect any treatment at the clinic. Surveys and interview data will be coded and all identifying information removed. Research data will be kept confidential and clinicians of the infertility clinic will not have access to research data from the study. Information gathered from the surveys will not be used for any other purpose other than the research described here. Participants may discontinue their involvement at any time and any data obtained from their survey will be destroyed. A summary of the findings will be available to participants, if requested, at the conclusion of the research project.

Sometimes as a result of taking part in research of this nature, issues can be raised for people that can be upsetting or which require further support or information. If this occurs, the infertility clinic has a professional counselling service that is available for all clients and this is available by contacting the clinic reception..

Participants may contact either the Research Supervisor or the Research Student if they have any queries about the research. If you have any comments about the research, please feel free to contact me (0732026207 or [andrea.jh@uqconnect.net](mailto:andrea.jh@uqconnect.net)) or my Supervisor Associate Professor Sandra Taylor, Central Queensland University on Tel: 07 4930 6598 or email: [s.taylor@cqu.edu.au](mailto:s.taylor@cqu.edu.au). If you would like to speak to someone who is not involved in the study, you can contact the Ethics officer at Central Queensland University on 07 49302602.

Thank you for taking the time to read this information sheet. Please retain for your future reference.

Thank you,

Andrea Hayward MSc(Hons)/Genetic Counsellor and PhD candidate

1





**Project title:**

**Women aged 35 and older: Their experiences, expectations and influences on decisions regarding Assisted Reproductive Technology for age-related infertility**

Researcher: Andrea Hayward, PhD student, School of Science, Engineering and Health, Central Queensland University

Research supervisor: Associate Professor Sandy Taylor, Head of the School of Science, Engineering and Health, Central Queensland University

**Informed consent**

I, \_\_\_\_\_ voluntarily consent to take part in this research project, which has been explained to me by

---

- I have received an Information Sheet to keep which provides full details of this research project.
- I understand that participation in the research involves filling in two questionnaires (one when first attending the clinic and another 6 months later).
- I understand that I may be invited also to be interviewed for the study but that I am free to accept or decline the invitation without penalty
- I understand the participation in this research is entirely voluntary and that I am free to withdraw from the study at any time without prejudice, or to withdraw permission to use any information that I have provided.
- I understand that the information I provide in the questionnaires and interviews will be kept in confidence and I will not be identifiable in any reports or publications which emerge from this research.

I have read the above statement and the Participant Information Sheet and give my consent to participate in the study

**Signature** \_\_\_\_\_

**Name (please print)** \_\_\_\_\_

**Date** \_\_\_\_/\_\_\_\_/\_\_\_\_

## **Appendix 5**

### **Information sheets and participant consent forms: Survey D**

## Participant Information sheet

### **Project Title:**

Women aged 35 and older: Their expectations, experiences, and decisions regarding Assisted Reproductive Technology (ART)

### **Research Team Contacts**

#### **Principal Researcher**

Andrea Hayward  
PhD Student UQ School of Medicine  
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#### **Principal Supervisor**

Dr. Tracey Papinczak Email: [tapapinczak@gmail.com](mailto:tapapinczak@gmail.com)

#### **Associate Supervisor:**

Dr. David King  
UQ School of Medicine Phone: 07 3365 5382 Email: [d.king@uq.edu.au](mailto:d.king@uq.edu.au)

#### **Description of the research:**

The purpose of this study is to explore the experiences and expectations of women who are having treatment at an infertility clinic. Women who are aged 35 or older, and participating in Assisted Reproductive Technology, are asked to participate in a focus group session.

The research will focus on your expectations of IVF technology, your beliefs on the success of IVF, whether your expectations have changed after having IVF treatment, whether you believe your expectations were realistic, whether the media had a role in shaping your expectations of IVF, and whether marketing information of IVF shaped your expectations of IVF. The focus group will also explore your knowledge of women's fertility declining with age and the concept of the 'biological clock'.

The research will also focus on your experience of IVF treatment. These questions will not discuss your opinions of Life Fertility, but your general experience of the medical, emotional and psychological aspects of having IVF treatment. Other topics open to discussion will include: the social influences or impediments for having children when aged 35 or older, whether relationship issues, career, education, or economic reasons have influenced having children at this time.

#### **Participation:**

Your participation in this project is voluntary. If you do agree to participate, you may withdraw at any time during the project without comment. Your decision to participate will in no way impact on your involvement with Life Fertility.

The interview format will be a semi-structured discussion based on the topics as described above. The setting will be informal and it is hoped that you chat freely about your IVF experience under the guidance of the facilitator. There will not be any financial reimbursement for participating in the focus groups. The session will be audio recorded. Your first names only will be used in the

tapes, and each participant will be given a pseudonym when the tapes are transcribed to preserve your anonymity. No identifying information will be recorded in the focus groups.

**Expected benefits:**

It is expected that this study will provide benefits to the knowledge of women having IVF treatment. Many medical studies have discussed treatments and technology but very few studies have explored the issues for Australian women who have experienced IVF treatment.

**Risks:**

This project may result in some emotional discomfort or anxiety during the focus group session. Conversely, you may find the discussion beneficial to you. Should you become distressed at any time during the focus group the focus group will be halted and you may choose to leave the discussion – please let the facilitator know. Free independent counseling is available through Lifeline on 13 11 14. Counselling and support services are available through Life Fertility.

**Confidentiality:**

You will be asked to sign a consent form before participating in the focus group. All comments and responses will be confidential and viewed only by members of the research team. Your name will be replaced by a pseudonym for the transcription of the focus group session and in the research document. No study or published document will identify you personally.

**Questions or Further information on this project:**

Please contact the principal researcher for information on this focus group research.

**Concerns or complaints regarding the conduct of this research:**

This study has been cleared by one of the human ethics committees of the University of Queensland in accordance with the National Health and Medical Research Council's guidelines. The University of Queensland is committed to researcher integrity and the ethical conduct of research projects. However, if you have any concerns or complaints about the ethical conduct of this research please contact the School of Medicine Research Ethics Unit on 07 3365 3924 or email [humanethics@research.uq.edu.au](mailto:humanethics@research.uq.edu.au). The Research Ethics Unit is not connected with the research project and can facilitate a resolution to your concern in an impartial manner.

Thank you for your assistance in this research,

Andrea Hayward MSc(Hons)

## **Informed Consent Form**

Women aged 38 and older: Their experiences, expectations and influences on decisions regarding Assisted Reproductive Technology for age-related infertility

Researcher: Andrea Hayward, PhD student, School of Medicine, University of Queensland

Research supervisor: Dr. Tracey Papinczak, University of QLD

Dr. David King, School of Medicine, University of QLD

I, \_\_\_\_\_ voluntarily consent to take part in this research project, which has been explained to me by

- 
- I have received an Information Sheet to keep which provides full details of this research project.
  - I understand that participation in the research involves a phone interview or a face to face interview with Dr. Suzie King.
  - I understand the participation in this research is entirely voluntary and that I am free to withdraw from the study at any time without prejudice, or to withdraw permission to use any information that I have provided.
  - I understand that the information I provide in the interviews will be kept in confidence and I will not be identifiable in any reports or publications which emerge from this research.

I have read the above statement and the Participant Information Sheet and give my consent to participate in the study.

Name (please print) \_\_\_\_\_

Signature \_\_\_\_\_

Date    \_\_\_\_ / \_\_\_\_ / \_\_\_\_

**Appendix 6**

**Ethical approval Surveys A, B, C and D**

Ms. Andrea Hayward MSc (Hons)  
Genetic Counsellor,  
Queensland Fertility Group,  
1<sup>st</sup> Floor, Watkins Medical Centre,  
225 Wickham Terrace,  
BRISBANE. Q 4000

8.12.06

Dear Andrea,

**Re: Research Proposal "The Expectations of the Older Woman with  
Age-related infertility around Assisted Reproductive Technology"**

I thank you for presenting to the Ethics Committee on Monday 20<sup>th</sup> November 2006 on the above project.

The Committee were impressed with the presentation, and look forward to hearing the outcome of the research, which they saw as a very useful project which would fill a gap in knowledge in this area.

It is noted that the Project should conclude on 1.1.08.

Consent Form and information sent to prospective participants were noted.

Should there be any concerns regarding the Project as it progresses, I should be pleased if you would advise me, and further, if for any reason you cease the Project before completion, I would require your advice.

A Progress Report in July 2007 is required also.

I am sorry you were detained prior to the presentation, and offer our best wishes for a most successful project.

Please accept my apologies for this emailed letter, but my printer is away for Service, and I wished you to receive it as soon as possible.

With best wishes also for the Festive Season,

Yours sincerely,

Pixie Annat  
Chairman  
QFG Ethics Committee.

**MEMORANDUM**

*From the Office of Research*



**Central Queensland  
UNIVERSITY**

*Secretary, Human Research Ethics Committee*

*Ph: 07 4923 2603*

*Fax: 07 4923 2600*

*Email: ethics@cqu.edu.au*

14 August 2006

Andrea Hayward  
Science/Engineering/Health  
Central Queensland University

Dear Ms Hayward,

**HUMAN RESEARCH ETHICS COMMITTEE  
EXPEDITED ETHICAL APPROVAL  
PROJECT H06/07-137, THE EXPECTATIONS OF THE OLDER WOMAN WITH  
AGE-RELATED INFERTILITY AROUND ASSISTED REPRODUCTIVE  
TECHNOLOGY.**

The Human Research Ethics Committee is an approved institutional ethics committee constituted in accord with guidelines formulated by the National Health and Medical Research Council (NHMRC) and governed by policies and procedures consistent with principles as contained in publications such as the joint Australian Vice-Chancellors' Committee and NHMRC *Statement and Guidelines on Research Practice*.

On 11 August 2006, the Chair of the Human Research Ethics Committee of Central Queensland University granted expedited ethics approval for the research project, *The Expectations of the Older Woman with Age-Related Infertility around Assisted Reproductive Technology*. This approval is subject to ratification by the whole committee at the next scheduled meeting.

The period of ethics approval is 11 August 2006 to 30 January 2007. The approval number is H06/07-137, please quote this number in all dealings with the Committee.

The conditions of approval for this research project are that:

- (a) You provide a letter of approval from participating organisations.
- (b) You refer clients to free counselling service and provide the phone number of counselling service on the information sheet
- (c) You advise in the information sheet how long the questionnaire & interviews will take

**Please lodge the above information by e-mail or memo with the Secretary, Human Research Ethics Committee within fifteen (15) working days upon the receipt of this advice or contact the Secretary and negotiate an appropriate due date.**

We recommend that you structure your response clearly by using each condition as a heading and addressing your response below it. Please ensure all necessary supporting material is attached to the response.



the Chair of the Human Research Ethics Committee by no later than the next working day after recognition of an adverse occurrence/event.)

- (c) you provide the Human Research Ethics Committee with a written "Annual Report" by no later than 28 February each calendar year and "Final Report" by no later than one (1) month after the approval expiry date;

(A copy of the reporting pro formas may be obtained from the Human Research Ethics Committee Secretary, Sue Evans, contact details given on the first page.)

- (d) if the research project is discontinued, you advise the Committee in writing within 5 working days of the discontinuation;
- (e) you comply with each and all of the above conditions of approval and any additional conditions or any modification of conditions which may be made subsequently by the Human Research Ethics Committee;
- (f) you advise the Human Research Ethics Committee (email: [ethics@cqu.edu.au](mailto:ethics@cqu.edu.au)) immediately if any complaints are made, or expressions of concern are raised, in relation to the project.

Please note that failure to comply with the conditions of approval and the *National Statement on Ethical Conduct in Research Involving Humans* may result in withdrawal of approval for the project.

You are required to advise the Secretary in writing within five (5) working days if this project does not proceed for any reason. In the event that you require an extension of ethics approval for this project, please make written application in advance of the end-date of this approval. The research cannot continue beyond the end date of approval unless the Committee has granted an extension of ethics approval. Extensions of approval cannot be granted retrospectively. Should you need an extension but not apply for this before the end-date of the approval then a full new application for approval must be submitted to the Secretary for the Committee to consider.

If you have any queries in relation to this approval or if you need any further information please contact the Secretary, Sue Evans or myself.

Yours sincerely,



Associate Professor Ken Purnell  
Chair, Human Research Ethics Committee

Cc: Project File  
Dr Sandra Taylor

Application Category: B

**MEMORANDUM**  
*From the Office of Research*



Secretary, Human Research Ethics Committee  
Ph: 07 4923 2603  
Fax: 07 4923 2600  
Email: [ethics@cqu.edu.au](mailto:ethics@cqu.edu.au)

14 December 2006

Andrea Hayward  
163 Priors Pocket Road  
Moggill QLD 4070

Dear Ms Hayward,

**HUMAN RESEARCH ETHICS COMMITTEE  
EXPEDITED ETHICAL APPROVAL  
PROJECT H06/07-137, THE EXPECTATIONS OF THE OLDER WOMAN WITH  
AGE-RELATED INFERTILITY AROUND ASSISTED REPRODUCTIVE  
TECHNOLOGY.**

The Human Research Ethics Committee is an approved institutional ethics committee constituted in accord with guidelines formulated by the National Health and Medical Research Council (NHMRC) and governed by policies and procedures consistent with principles as contained in publications such as the joint Australian Vice-Chancellors' Committee and NHMRC *Statement and Guidelines on Research Practice*.

On 14 December 2006, the Chair of the Human Research Ethics Committee of Central Queensland University acknowledged full compliance with the conditions placed on ethics approval for the research project, *The Expectations of the Older Woman with Age-Related Infertility around Assisted Reproductive Technology*. Approval was also given to extend the dates of the project, due to the delay experienced in obtaining ethical approval from Queensland Fertility Group.

The period of ethics approval is 11 August 2006 to 30 January 2008. The approval number is H06/07-137, please quote this number in all dealings with the Committee.

The standard conditions of approval for this research project are that:


- (a) you conduct the research project strictly in accordance with the proposal submitted and granted ethics approval, including any amendments required to be made to the proposal by the Human Research Ethics Committee;
- (b) you report immediately anything which may warrant review of ethics approval of the project, including:
  - (i) serious or unexpected adverse effects on participants;
  - (ii) proposed changes in the protocol;
  - (iii) unforeseen events that might affect continued ethical acceptability of the project;

(A written report of any adverse occurrence or unforeseen event that might affect the continued ethical acceptability of the research project must be submitted to

If you have any queries in relation to this approval or if you need any further information please contact the Secretary, Sharyn Mitchell or myself.

Yours sincerely,

---



Associate Professor Ken Purnell  
Chair, Human Research Ethics Committee

Cc: Project File  
Dr Sandra Taylor

Application Category: B

**MEMORANDUM**  
*From the Office of Research*



*Secretary, Human Research Ethics Committee*

*Ph: 07 4923 2603*

*Fax: 07 4923 2600*

*Email: ethics@cqu.edu.au*

10 July 2008

Ms Andrea Hayward  
163 Priors Pocket Road  
Moggill QLD 4070

Dear Ms Hayward,

**HUMAN RESEARCH ETHICS COMMITTEE ETHICAL APPROVAL -  
MODIFICATION TO PROJECT H06/07-137, *WOMEN AGED 38 AND OLDER:  
THEIR EXPERIENCES, EXPECTATIONS AND INFLUENCES ON DECISIONS  
REGARDING ASSISTED REPRODUCTIVE TECHNOLOGY FOR AGE RELATED  
INFERTILITY***

The Human Research Ethics Committee is an approved institutional ethics committee constituted in accord with guidelines formulated by the National Health and Medical Research Council (NHMRC) and governed by policies and procedures consistent with principles as contained in publications such as the joint Universities Australia and NHMRC *Australian Code for the Responsible Conduct of Research*.

On 10 July 2008, the Human Research Ethics Committee of Central Queensland University granted approval to modify the research project, *Women aged 38 and older: Their experiences, expectations and influences on decisions regarding assisted reproductive technology for age related infertility*. The modification is to provide an electronic copy of the survey to a support group for circulation to members.

The period of ethics approval is now 11 August 2006 to 30 January 2009. The approval number is H06/07-137, please quote this number in all dealings with the Committee.

The standard conditions of approval for this research project are that:

- (a) you conduct the research project strictly in accordance with the proposal submitted and granted ethics approval, including any amendments required to be made to the proposal by the Human Research Ethics Committee;
- (b) you report immediately anything which may warrant review of ethics approval of the project, including:
  - (i) serious or unexpected adverse effects on participants;
  - (ii) proposed changes in the protocol;
  - (iii) unforeseen events that might affect continued ethical acceptability of the project;

(A written report of any adverse occurrence or unforeseen event that might affect the continued ethical acceptability of the research project must be submitted to

the Chair of the Human Research Ethics Committee by no later than the next working day after recognition of an adverse occurrence/event.)

- (c) you provide the Human Research Ethics Committee with a written "Annual Report" by no later than 28 February each calendar year and "Final Report" by no later than one (1) month after the approval expiry date;

(A copy of the reporting pro formas may be obtained from the Human Research Ethics Committee Secretary, Sue Evans, contact details given on the first page.)

- (d) if the research project is discontinued, you advise the Committee in writing within 5 working days of the discontinuation;
- (e) you comply with each and all of the above conditions of approval and any additional conditions or any modification of conditions which may be made subsequently by the Human Research Ethics Committee;
- (f) you advise the Human Research Ethics Committee (email: [ethics@cqu.edu.au](mailto:ethics@cqu.edu.au)) immediately if any complaints are made, or expressions of concern are raised, in relation to the project.

Please note that failure to comply with the conditions of approval and the *National Statement on Ethical Conduct in Human Research* may result in withdrawal of approval for the project.

You are required to advise the Secretary in writing within five (5) working days if this project does not proceed for any reason. In the event that you require an extension of ethics approval for this project, please make written application in advance of the end-date of this approval. The research cannot continue beyond the end date of approval unless the Committee has granted an extension of ethics approval. Extensions of approval cannot be granted retrospectively. Should you need an extension but not apply for this before the end-date of the approval then a full new application for approval must be submitted to the Secretary for the Committee to consider.

If you have any queries in relation to this approval or if you need any further information please contact the Secretary, Sue Evans or myself.

Yours sincerely,



Dr Lorna Moxham  
Chair, Human Research Ethics Committee

Cc: Project File  
Associate Professor Sandra Taylor (supervisor)

Application Category: A



THE UNIVERSITY OF QUEENSLAND  
Institutional Approval Form For Experiments On Humans  
Including Behavioural Research

**Chief Investigator:** Ms Andrea Hayward  
**Project Title:** Women Aged 35 And Older: Their Expectations, Experiences And Decisions Regarding Assisted Reproductive Technology (ART)  
**Supervisor:** Dr Tracey Papinczak, Dr David King  
**Co-Investigator(s)** None  
**Department(s):** School of Medicine  
**Project Number:** 2011000456  
**Granting Agency/Degree:** PhD  
**Duration:** 31st December 2011

**Comments:**

**Name of responsible Committee:-**

**Behavioural & Social Sciences Ethical Review Committee**

This project complies with the provisions contained in the *National Statement on Ethical Conduct in Human Research* and complies with the regulations governing experimentation on humans.

**Name of Ethics Committee representative:-**

**Associate Professor John McLean**

**Chairperson**

**Behavioural & Social Sciences Ethical Review Committee**

Date

8/9/2011

Signature