Life After Infertility: A Grounded Theory of Moving on from Unsuccessful Fertility Treatment

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June 2017

Submitted to the University in partial fulfilment of the requirements
of the degree of Doctor of Clinical Psychology

Portfolio Volume 1: Major Research Project

Acknowledgements

Firstly, I would like to thank my research supervisor Dr Helen Ellis-Caird who has been incredibly generous with her time, guidance, and support with this project. I would also like to thank my external supervisor Dr Carla Croft whose knowledge and expertise in the field has been of immense value to this project.

I would like to thank my family, friends, and especially Kiernan, who have all offered me so much love, encouragement and support along the way. Also thanks to my amazing classmates in cohort 14.

Finally, I would like to give my sincere thanks to the women who participated in this study, who so generously shared their time and their experiences, and who made this study possible.

Abstract

Despite the many advances of medical technology to help treat infertility, approximately half of women seeking fertility treatment will never give birth to a child. Women coping with treatment failure face many challenges, including deciding when to abandon treatment and how to let go of their dreams of having a baby to focus on other pursuits. In order to better understand how women cope with these challenges, in depth interviews and a focus group were carried out with 12 women for whom fertility treatment had not been successful. Data was gathered and analysed using Grounded Theory, and a model of the process of adjustment from pursuing treatment to coming to terms with involuntary childlessness was co-constructed from the data.

The model conceptualizes women's journey as moving through three main phases; 'living in limbo' in which women are still undergoing treatment, 'leaving treatment' in which women decide to terminate treatment and abandon the search for a resolution to their infertility, and finally 'learning to live with involuntary childlessness' in which women start the 'work' of grappling with the questions that childlessness seems to raise about the meaning of their lives, their identity and self image, and their sense of social belonging. The model goes on to highlight the factors which seem to aid women in resolving these challenges.

The findings of this study suggest that the emotional challenges of coping with unsuccessful fertility treatment extend well beyond the end of treatment, highlighting the need for good access to therapeutic support for women coping with involuntary childlessness longer term. Results also point to certain sources and types of support which may be particularly helpful, including peer support from other childless women, and therapeutic interventions which help women develop more positive perspectives on childlessness and to identify alternative sources of fulfillment. The results of this study also point to the need for social action which works to challenge the misconceptions and stigma surrounding infertility and childlessness which add a further challenge to the lives of women who are involuntarily childless.

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Chapter 1: Introduction

"To want and not to have, sent all up her body a hardness, a hollowness, a strain. And then to want and not to have- to want and want- how that wrung the heart, and wrung it again and again!"

— Virginia Woolf, To the Lighthouse

1.1 Overview

The main aim of this introductory chapter is to orient the reader to the field of psychological experiences of infertility, and to set up the rationale for the research project which will follow. I will start by introducing some key facts and terms associated with infertility, fertility treatment and childlessness, as well as explaining my personal interest and epistemological stance when approaching this area of research. I will summarize what the research literature can tell us about the psychological impact of infertility and fertility treatment. This will be followed by a systematic review of the research literature on women's lived experience of moving on from unsuccessful fertility treatment. This chapter will conclude by establishing the rational and research aims guiding this study.

1.2 Background and definition of terms

Whether one views the desire for children and as biologically driven or culturally motivated, most couples across cultures endeavour to have a baby (Inhorn & Van Balen, 2002). However, not all of these couples find it easy to become pregnant. In industrialized countries, one out of six couples struggle with *infertility*, which is defined as the inability to conceive after one year of unprotected intercourse (Bhattacharya et al. 2010). There are a myriad of factors affecting both men and women's fertility which can contribute to difficulties becoming pregnant, including problems with regular ovulation, medical conditions, low sperm count and age. However, in about a quarter of cases no specific cause can be identified, and couples are diagnosed as having *medically unexplained infertility* (Human Fertilisation and Embryology Authority [HFEA], 2014).

Many of those struggling with infertility will turn to medical interventions to help them get pregnant. In Britain, approximately 55,000 women undergo fertility treatment every year (HFEA, 2014). *Fertility treatments* are medical interventions for infertility which may include medications to stimulate ovulation, surgery, or more 'high tech' techniques (referred to as *Assisted Reproductive Technologies* [*ART]*), like *in vitro fertilization* (*IVF*), *intrauterine insemination* (*IUI*), *intra-cytoplasmic sperm injection* (*ICSI*) and *donor insemination* (*DI*). IVF is the most common procedure, and involves removing eggs from a woman's ovaries and fertilizing them in a laboratory. One or more fertilized eggs are then returned to the woman's womb to develop. NICE guidelines suggest that three cycles of IVF should be offered to women (under 42) who have not become pregnant after two years of unprotected sexual intercourse, or who have not become pregnant after 12 cycles of *artificial insemination* (a procedure in which sperm is directly inserted in a woman's womb to help her conceive) (National Institute for Clinical Excellence [NICE], 2013).

Despite NICE recommendations, access to NHS funded IVF treatment can vary considerably across the UK, and waiting times can be long, leading the majority of couples (6 out of 10) to pay for their own treatment at private fertility clinics, (at approximately £5,000 per cycle) (HFEA, 2014). IVF can be a physically demanding and an often costly endeavour, and sadly is not successful for many couples. Whilst nearly four times as many women are undergoing fertility treatment now compared to 15 years ago, success rates remain low (HFEA, 2007; HFEA, 2014). At present, just 25% of IVF attempts lead to live births, whilst 75% do not (HFEA, 2014).

Despite the fact that fertility treatments have become a powerful medical tool helping millions of people achieve their hopes of having a baby, for some, treatment will not be successful, leaving many to cope with *unresolved infertility,* defined as infertility which is not resolved with treatment. A recent survey of UK women aged 40-55 found that, of those who wanted to have children, 16% had consulted a doctor for problems conceiving, 8% had received fertility treatment, and 4% remained involuntarily childless at the end of their reproductive life (Berrington, 2015). These finding are consistent with research from the United States that approximately 35% - 50% of those who undergo medical treatment for infertility are not successful in having a baby (Cosineau & Domar, 2007; William M. Mercer Co., 1997). Amongst those for whom fertility treatment is not successful, research has found that a minority of couples (11% to 21%) will go on to successfully adopt a child after leaving treatment (Sydsjö, Svanberg, Lampic & Jablonowska, 2011; Walschaerts et al., 2013; Troude et al., 2016).

In the public discourse the term *involuntary childlessness* has come to include those who wanted to, but do not have children for a variety of reasons including life circumstances like not meeting the right partner in time, as well as infertility, and is distinguished from those who are *voluntarily childless* (those who have chosen not to have children). In this paper the term *involuntary childlessness* will refer to infertile women who remain without biological children despite trying to become pregnant using fertility treatment. How these women experience unsuccessful treatment, how they know when it is time to stop “trying” for a baby, and what happens after this decision is made will be the topic of this dissertation.

1.3 Personal and Epistemological position

1.3.1 Personal interest

I’ve long been interested in the psychology of becoming a parent, and I conducted my Masters research on women’s experiences of depression following pregnancy. When my research supervisor highlighted fertility treatment as an area of research interest for her, I started to read about the topic. I felt surprised learning about the prevalence of infertility issues, and about the low success rates of treatments like IVF. This also sparked a strong feeling of curiosity and concern about what happens to those for whom fertility treatment is not successful. As a professional, I felt ill equipped to consider how I might support someone coping with infertility or involuntary childlessness, and reflected that this was not something touched upon in any of my training as a clinical psychologist thus far.

On a personal level, I came to this study naïve about the experiences of women struggling with infertility. I’ve never gone through fertility treatment, nor have I tried or struggled to become pregnant. I don’t have any children, although I hope to one day. Despite this, as a woman in her early 30’s fertility related anxiety is a common topic in my social context. Like many of my peers, education and work pursuits have meant thinking about children has come much later than my parent’s generation. I think several factors, including changing social roles and opportunities for women, changing attitudes towards choosing not to have children, and the increasing prevalence of fertility treatments have created a more complicated relationship with the prospect of motherhood for women today than ever before. I think my awareness of some of these tensions and anxieties have undoubtedly contributed to my choice of this topic.

1.3.3 Epistemological position

I identify with holding a social constructionist position when approaching this research. Social constructionism questions the notion that that there is an objective reality or "real truth" which can be discovered through scientific research. Instead, it is thought that "reality" is co-constructed between people within a specific cultural and historical context (Burr, 2003). Therefore, when approaching the study of a phenomenon like infertility, I have tried to hold in mind that how infertility is conceptualized (whether it be an 'illness', or considered 'good' or bad') cannot be taken for granted, but rather is bound up in our current cultural context. Therefore, when attempting to understand the psychological experience of something like infertility, one must consider that the social discourses available to women in this culture and at this point in history will influence how they think, feel, and describe their experience of infertility. This motivated my choice to conduct a qualitative study which explores women's descriptions of living through unsuccessful fertility treatment within a social and cultural context.

This project does not attempt to get at the 'real truth' of how women experience unsuccessful fertility treatment, but it does attempt to provide a credible portrayal of this experience for a certain group of women, at a particular point in time, and through the lens of psychological adjustment. This portrayal will inevitability be influenced by my own subjective point of view and ways of seeing the world, and the results will be co-construction between myself and the participants of this study. My awareness of the role I play in this construction has highlighted the need for self reflexivity throughout the research process. I will attempt to demonstrate this self reflection through my use of reflective tools like a research diary and memos, through acknowledging my interpretations when presenting findings, and by making explicit how the resulting model developed in this study evolved as a co-construction between myself and participants over time.

1.4 The social context and social construction of infertility

Conceptualizations of infertility vary in different cultures, but certainly in most of the industrialized world infertility is currently viewed as a medical condition. The history of the increasing ‘medicalization’ of infertility has been linked with the development of fertility drugs in the 1950’s, and the rapid advances of Assisted Reproductive Technologies since the late 1970’s. Although infertility is currently viewed by many as a type of ‘illness’ best treated through medical intervention, as others have pointed out (Greil, Slauson-Blevins & McQuillan, 2010) no matter how the medical community might view them, men and women would not define themselves as infertile unless they view parenthood as a desired social role. The extent to which other social roles besides motherhood are available to women differs greatly in different parts of the world, which may have important implications for how infertility is experienced and viewed by others. For example, in Western cultures choosing not to have children is increasingly seen as socially acceptable, and growing numbers of women identify as “child-free” or “voluntary childless”. In cultures in which motherhood is a woman’s most important and perhaps only social role, there may be no concept of ‘voluntary childlessness’, making infertility more ‘visible’ as any married childless woman would be assumed to be infertile (Dyer, Abrahams, Hoffman, & Van der Spuy, 2002). In contrast, infertile women in western societies may often be assumed to be child-free, and infertility may be experienced more as a ‘secret stigma’ (Greil, 1991).

Certain life events, stressors, and medical conditions carry social stigma. This is certainly the case for infertility, which has long been linked with ideas around being less feminine or less masculine, of inadequacy and inferiority, and of social deviance (Whiteford & Gonzalez, 1995). As we go on to consider the literature on the psychological impact of infertility and infertility treatment it should be held in mind that this literature is emerging exclusively from Western societies and that this adjustment is taking place within a Westernised social context which largely views infertility and childlessness in a negative way.

1.5 The psychological impact of infertility and fertility treatment

There is large body of research literature exploring the emotional consequences of infertility, which have made links between infertility and martial distress (Benazon, Wright & Sabourin, 1992), social isolation (Cousineau & Domar, 2007) and poorer psychological wellbeing (Greil, 1997). In a large scale review of the research literature on the psychological impact of infertility Cousineau and Domar (2007) highlight that common reactions to infertility include depression, anxiety, and a feeling of loss of control over one's life. Although the stress of infertility seems to effect both men and women, research suggests that women may be more negatively impacted. Studies of psychological distress amongst couples have found that women find infertility more stressful (Jordan & Revenson, 1999), experience higher levels of depression and anxiety (Wright, Duchesne & Sabourin, 1991), and a greater loss to self esteem (Pasch, Dunkel-Schetter & Christensen, 2002) compared to their male partners. Studies exploring the prevalence of psychiatric disorders amongst infertile women have found significantly higher rates of major depressive disorder and anxiety disorders compared to norms (Oddens, Tonkelaar & Nieuwenhuyse, 1999; Chen, Chang, Tsai & Juang, 2004). Another study aimed at comparing the experience of infertility to other 'chronic medical conditions', found levels of depression and anxiety amongst infertile women were similar to those living with cancer, hypertension, and heart disease (Domar, Zuttermeister & Friedman, 1993).

There is a lack of consensus in the research literature about the impact of infertility and undergoing fertility treatment on couple relationships. A long term follow-up study of women who had completed fertility treatment 2-15 years previously found no significant differences in standardized measures of marital and sexual satisfaction between those who became biological mothers through IVF, those who had adopted, and those who remained childless (Leiblum, Aviv & Hamer, 1998). More recent studies exploring the impact on couple relationships of undergoing successful (Sydsjö *et al.*, 2002) and unsuccessful IVF (Sydsjö *et al.*, 2005) found that couples remained stable and satisfied in their relationships regardless of the outcome of treatment. Research from the quantitative (Peterson, Pirritano, Block & Schmidt, 2011; Schmidt, Holstein, Christensen & Boivin, 2005) and the qualitative literature (Webb & Daniluk, 1999) have highlighted the experience of living through infertility treatment may in fact bring partners closer together and strengthen relationships. There are, however, some who claim that infertility does have a negative impact on couple relationships and may be linked with marital breakdown for some couples (Wirtberg et al. 2007).

Research suggests that in addition to the challenges of living with infertility, the stress associated with undergoing fertility treatments may add an additional emotional burden, particularly for women. The process of undergoing fertility treatment often includes taking fertility drugs which can cause mood disturbances, frequent testing of blood and hormone levels, and invasive and often painful surgical procedures like IVF (Cousineau & Domar, 2007). Despite the many physical stressors of treatment, research suggests that those undergoing treatment describe the psychological rather than physical demands of treatment as the most distressing aspect (Eugster & Vingerhoets, 1999). Undergoing fertility treatment is commonly described in the research literature as an 'emotional roller coaster' as many patients experience cycles of hope and disappointment whilst undergoing rounds of treatment. Research showing a positive correlation between stress and the number of fertility tests and treatments received highlights that the psychological strain of treatment may increase over time (Abbey, Halman & Andrews, 1992; Bailey, Ellis-Caird & Croft, 2017). In order to get a better sense of the psychological consequences of coping with fertility treatment amongst women, a broad summary of research literature will now be considered.

1.5.1 Women's emotional adjustment to fertility treatment

Verkaak and colleagues (2007a) carried out a systematic review of the past 25 years of research on women's emotional adjustment to IVF. Their review included 27 quantitative studies which used standardized measures of anxiety, depression and general distress before, during, and after successful and unsuccessful IVF treatment cycles. Their review showed that although a disproportionate amount of the literature has focused on the stress of undergoing treatment itself, research suggests that this stress goes and stays away as soon as pregnancy is achieved. They conclude that it is the threat of treatment failure and the fear of "permanent infertility and eventual childlessness that constitutes the most important stressor in IVF treatment", and that IVF treatment itself causes no long term emotional consequences (Verhaak et al. 2007a, p.35).

With respect to emotional responses to *unsuccessful* IVF, the literature suggests that women experience elevated levels of depression and anxiety, with ranges of 10% (Lok et al., 2002) to 25% (Newton et al., 1990, Verkhaak et al., 2005) experiencing clinically relevant levels of depression following failed treatment. The small body of evidence on longer term emotional adjustment to unsuccessful treatment resulting in childlessness suggests that these symptoms do seem to improve over time. Cross sectional studies examining women's wellbeing 15 – 30 months after treatment (Weaver, Clifford, Hay & Robinson, 1997), 2 -3 years following treatment (Hammerberg, Astbury & Baker, 2001), and up to 13 years after treatment (Leiblum, Aviv & Hamer, 1998) did not find significant differences in measures of mental health status for women for whom IVF was successful or unsuccessful. However, results across these studied consistently showed that women for whom IVF was successful reported higher overall life satisfaction compared to women who remained childless.

1.5.2 Individual differences in emotional adjustment to fertility treatment

In order to better understand how social and psychological factors (like personality traits, social support, and coping strategies) might influence women's adjustment to fertility treatment, Rockliff and colleagues (2014) carried out a systematic review of 23 studies examining psychosocial factors associated with emotional adjustment to IVF. Studies showed consistent support for a positive relationship between neuroticism and increased distress. In contrast, social support was associated with lower levels of distress across multiple studies. Although several studies have suggested that coping which involves avoidance, escape and distraction are associated with higher levels of distress amongst IVF patients (Hynes, Callan, Terry & Gallois, 1992; Litt, Tennen, Affleck & Klock, 1992; Terry & Hynes, 1998), the authors acknowledge that different coping strategies might be appropriate at different points along the treatment journey. They conclude further research is needed to better understand the coping strategies which are most useful not only for coping with treatment itself, but also for longer term wellbeing of women coping with unsuccessful treatment.

In a 2007 study, (Lechner, Boleman & Dalen) addressed the issue that almost all the studies exploring coping focus on people who are still under treatment for infertility, and that coping strategies for those who are still hoping for pregnancy might differ considerably from those who are no longer pursuing treatment. In this cross sectional study 116 Dutch women and men who had undergone fertility treatment in the past but now considered themselves ‘definitely involuntarily childless’ were asked to complete measures of social support, health issues, grief, depression and anxiety, and active (ie. problem solving, directly intervening when there are difficulties) or passive coping styles (ie. withdrawing from others, feeling too overwhelmed to do anything). Results showed that women especially reported more health complaints, symptoms of depression and anxiety, and complicated grief compared to the general population. Results also showed that participants reporting a more active coping style had lower levels of anxiety, depression and complicated grief, while passive coping style and dissatisfaction with social support was positively associated anxiety, depression, and complicated grief.

In addition to social support and a more ‘active’ coping style, evidence suggests that women who make an active decision to pursue different life goals or avenues to parenthood following failed treatment seem to cope better compared to those who persist with hopes of pregnancy (Verhaak, Smeenk, Nahuis, Kremer & Braat, 2007b). In a longitudinal study of long term adjustment to fertility treatment, Verhaak and colleagues followed 298 women entering their first cycle of IVF/ICSI through to 3-5 years after treatment. Amongst those who had not been successful in having a baby through IVF, four ‘modes’ of adaptation were identified; ‘medical mode’ (still pursuing fertility treatment to have a biological child), ‘passive mode’ (still desiring a child, but not actively pursuing it), ‘alternative mode’ (pursuing other avenues to parenthood e.g. adoption), and ‘new goals’ (abandoning the desire to have a child and pursuing other life goals). Results showed significantly higher levels of depression and anxiety amongst women still hoping for pregnancy (either in the medical or passive mode) compared to the women who had moved forward either towards adoption or voluntary childlessness. The authors conclude that persisting with fertility treatment seems to have a negative effect on longer term adaptation for those facing unsuccessful fertility treatment.

1.5.3 Deciding to abandon unsuccessful fertility treatment

A recent systematic review of the past 20 years of research yielded 22 studies exploring the reasons and predictors of discontinuation from fertility treatment (Gameiro, Boivin, Peronace, & Verhaak, 2012). They found that the most frequently selected reason for opting out of treatment by patients was postponement of treatment for a later time, followed by “physical and psychological burden” and “relational and personal problems”. The authors raise the issue that these reasons are vague and ambiguous, and conclude that our current knowledge about causes of discontinuation is still very limited. It is also interesting to note that the most cited reason for discontinuation was not a decision to end treatment at all, but a postponement of treatment, perhaps reflecting avoidance in patients and a wish to delay this difficult decision for a later time.

1.6 Understanding adaptation to transitions – a theoretical perspective

Schlossberg's (1981) Model of Transitions in adulthood provides a useful framework for considering some of the unique challenges of adapting to unsuccessful fertility treatment and involuntary childlessness. Within this framework *transition* is conceptualized as occurring when "an event or non-event results in a change in assumption about oneself and the world and this requires corresponding change to one's behaviour and relationships" (p.5). The idea that life events or changes which are expected but then fail to occur (so called "non-events") may be equally significant as life events which do (like graduating from University, getting married, or coping with a bereavement) seems to hold particular relevance for the experience of infertility, as women are coping with the 'missing' life event of having a baby and becoming a mother. Schlossberg conceptualizes *adaptation* to transition as "a process during which an individual moves from being totally preoccupied with the transition to integrating the transition into his or her life" (p. 7) and suggests that adaption is mediated by a number of individual and external variables.

According to Schlossberg's model, the factors influencing adaptation to a particular transition can be divided into three broad categories; (1) characteristics of the particular transition (like whether the transition is associated with losing or gaining a certain role, is gradual or sudden, and whether the change is expected to be permanent, temporary, or uncertain), (2) the characteristics of the pre and post transition environments (like levels of social or institutional support), and (3) the characteristics of the individual experiencing the transition (like age, health, personal values and psychosocial competencies). Within the context of infertility, this model suggests that when attempting to understand a transition like adapting to unsuccessful fertility treatment, it may be important to consider not only individual characteristics like personality traits or coping style, but also the *post transition environment* like levels of social or institutional support for women with unresolved fertility, and the *characteristics of the particular transition* like whether women view their infertility or childlessness as permanent, temporary or uncertain. Schlossberg highlights that transitions which are uncertain in their duration may be the most difficult to adapt to, as individuals do not have the comfort of knowing that the change they are facing is only temporary, or the certainty of knowing that a change needs to be permanently integrated into one's life.

This seems to hold particular relevance for women undergoing fertility treatment, as the potential for endless treatment options may mean that for many, there is no clearly defined 'end' to treatment. Furthermore, the possibility of treatment success or even of a natural pregnancy after ending treatment may mean that many women remain uncertain whether infertility and involuntary childlessness is something temporary they need to live through or a permanent reality they need to adapt to. As such, Schlossberg's model highlights why adjustment to involuntary childlessness may be so complicated for women undergoing fertility treatment.

1.7 Psychological adjustment following unsuccessful fertility treatment: A systematic review of women's lived experience.

The research above has highlighted that the experience of infertility and coping with fertility treatment is a psychologically stressful experience, and women in particular are at risk of experiencing depression and anxiety. However, what emerges from the literature is that these experiences tend to be temporary, with pregnancy quickly relieving the negative psychological effects of infertility. Those that are most psychologically impacted long term appear to be those coping with unsuccessful treatment and the threat of involuntary childlessness, and particularly those who persist with fertility treatments despite treatment failure over time. Whilst the quantitative research literature on personality factors, coping style, and 'modes' of adaptation offer some insight about the factors which might contribute to women's adjustment to unsuccessful treatment and long term infertility, it tells us little about the subjective experience of living through this process. Furthermore, the literature thus far has told us little about how women are able to exit the cycle of ongoing treatment and 'move on' when treatment has not been successful. The focus on gathering information from studies offering insight into lived experience meant that only qualitative studies were included in the systematic review.

In order to shed more light on the current knowledge base on women's lived experience of moving on from unsuccessful fertility treatment, a systematic review of the peer-reviewed literature was carried out. The search produced 12 relevant articles which will be summarized below. Together, these papers will describe women's experiences of deciding to stop fertility treatment, the aftermath of this decision, and experiences of infertility and involuntary childlessness over time. This will be followed by an evaluation of the quality of the current body of research evidence.

1.7.1 Search strategy

The search strategy focused on identifying papers which examined women's experience and adjustment to ending unsuccessful fertility treatments. Terms were identified through reading of the literature around infertility and coping, through consultation with my research supervisors, and through database suggestions of related terms (see *Table 1* for a summary or search terms). Terms were truncated as appropriate (e.g. adjust* = adjustment, adjusting), and alternative spellings were considered (fertilisation, fertilization) to ensure all relevant articles were captured. Literature starting from 1978 was included in the search, which marks the first birth of a child from IVF (HFEA, 2009).

Table 1: Search Terms Used in Systematic Literature Search

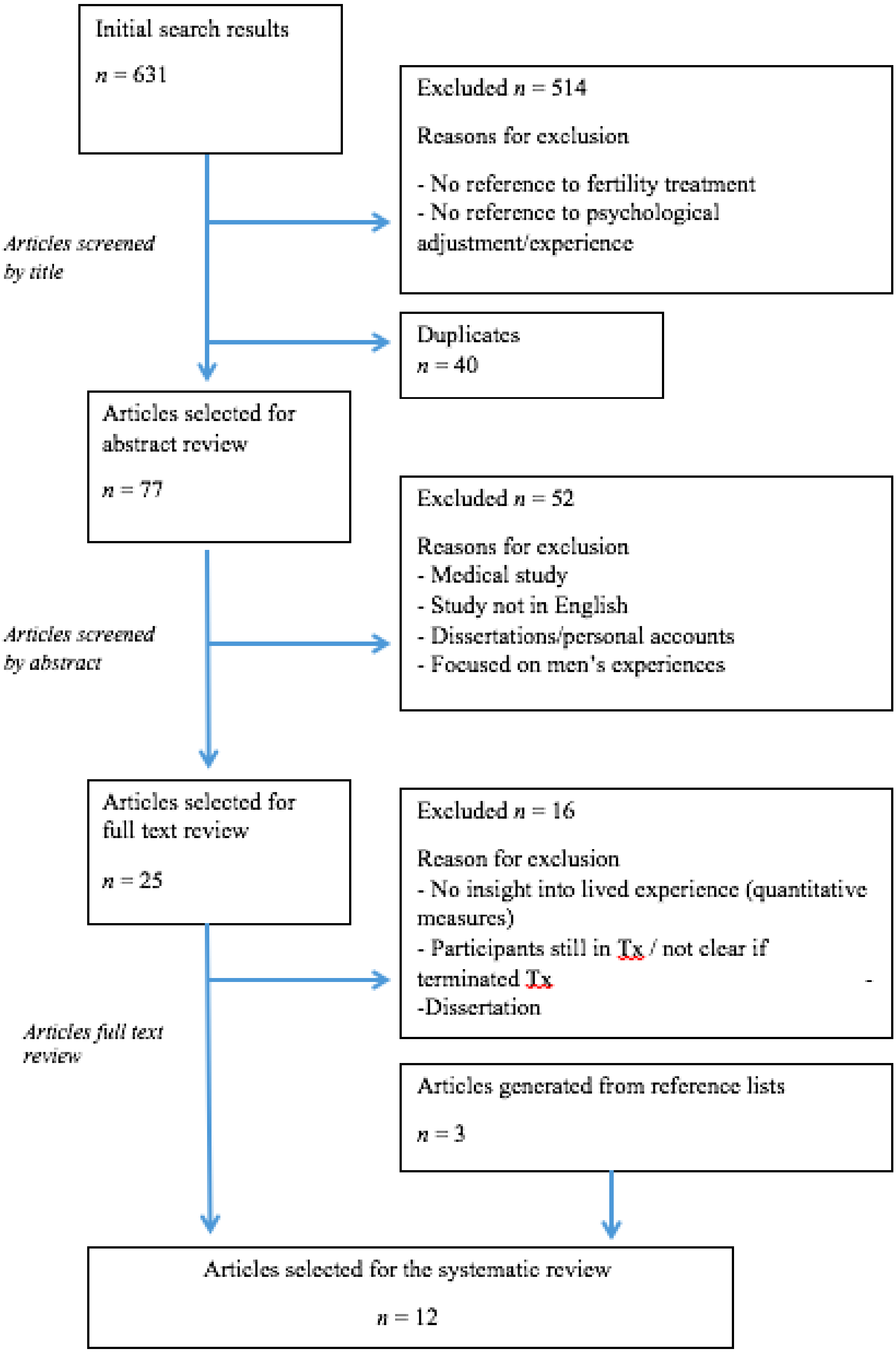
Fertility treatment		**Ending**		**Adjustment**
Infertility treatment IVF In vitro fertilization Assisted reproductive technology Fertility treatment Fertilization in vitro	*AND*	End/Ending Drop out Discontinuation Stopping Moving on Unsuccessful Failure Letting go Abandoning Decision making	*AND*	Adjustment Adaptation Transition Coping Mental health Resilience Greif Crisis Psychology Perception Experience Emotion Distress Childlessness

Searches were carried out in Scopus, Cinhal, and Pub Med databases, generating 631 papers. Titles of each paper were reviewed, and papers were excluded if no reference was made to fertility treatment and psychological adjustment/experience. After accounting for duplicates, the remaining 77 paper's abstracts were reviewed and excluded based on the inclusion and exclusion criteria (see *Table 2*). At this stage papers were excluded if they did not focus on women's lived experience (but rather on quantitative data and psychosocial measures), if they did not include the experiences of women, if the study was not clear whether participants had terminated treatment, and if the study was not in English. The remaining 25 articles were read in full text, and reference lists were hand searched to identify any other relevant articles not generated by the database search. The literature search ultimately generated 12 journal articles for review. A flow chart summarizing the search process is shown in *Figure 1*.

Table 2: Literature Search Inclusion and Exclusion Criteria

Inclusion criteria	**Exclusion criteria**
Study focused on women's lived experience of unsuccessful fertility Tx	No insight on lived experience (ie. reliant on data from questionnaires/ psychometric measures), medical studies
Focused on experiences of women or women in couples	Focused on experiences of men
Must focus on participants who have terminated treatment	Participants still in Tx, or study not clear if participants have terminated fertility Tx
Study must be published in English	Dissertations and personal accounts

Figure 1. Flow Chart of Literature Search Process



1.7.2 Summary of papers

All of the 12 papers reviewed were qualitative, and employed a range of methodologies including narrative inquiry, thematic analysis, phenomenological approaches and grounded theory. One study employed a longitudinal design, whilst the remaining 10 were cross-sectional. All of the studies explored the experience of women, and a proportion also included male partners. With regards to the time since stopping treatment the majority of studies examined the experience of women 3-months to 5 years after stopping fertility treatment. One study included a proportion of participants still in fertility treatment in order to compare their experiences to participants who had stopped treatment. One study explored the experience of women 20 years after ending unsuccessful treatment. Only one study specifically focused on women's experiences of the decision making process around stopping treatment. Sample sizes varied, the lowest being 8 and the highest being 74 (37 couples). The studies were conducted in a range of different countries including Canada, the United States, Sweden, Taiwan, China and the UK. A full summary of each paper is included in *Table 3*.

I will start my summarizing the research on women's experiences of deciding to stop fertility, followed by research exploring how women experience the aftermath of this decision. I will then go on to summarize the research exploring women's adjustment to permanent infertility and involuntary childlessness over time.

Table 3 - Summary of Studies Included in Systematic Literature Review

Authors & Title	**Aims of study**	**Participants**	**Method (sampling, data collection, data analysis)**	**Key findings and conclusions**	**Main strengths and limitations**
Bergart (2000) *The experience of women in unsuccessful fertility treatment: What do patients need when medical intervention fails?* **USA**	To understand how women viewed their lives after ending unsuccessful fertility Tx	10 women at least 6 months since terminating Tx, all childless (no info about mean/range of time since stopping Tx)	Participants recruited through infertility support organization, 3 interviews carried out with each participant, data gathered and analysed using grounded theory approach	- Found women reported intense feelings of inadequacy and personal failure, grief, and guilt in coping with unsuccessful fertility Tx - Although some satisfied with Tx from infertility specialist, majority reported dissatisfaction with level of emotional support, feel given false hope - Conclude medical professionals should offer more sensitive and personalized care, offer realistic assessments of likelihood of success	(+) Provide list of practical guidelines for medical professionals treating infertility based on findings (-) Very limited information about study itself (which was based on Doctoral dissertation) no details of process of data gathering, analysis, measures taken to ensure credibility of findings, making quality of research difficult to judge
Blenner (1990) *Passage through infertility: A stage theory* **USA**	To explore perceptions that couples have of their infertility during different phases of their treatment	24 married couples, a minority with previous biological children, ranged from in Tx to post Tx (no details of how long post Tx)	No details of sampling method, recruited through infertility conference/support groups/newsletter/brochures, open ended interviews in participants homes, data gathered and analysed using symbolic internationalism and grounded theory	- Results showed 8 stages couples pass through; dawning of awareness, having hope and determination, intensifying treatment, spiralling down, letting go, quitting and moving out, and shifting focus - Conclude that awareness of stages among professionals and patients could help patients anticipate and better cope with long-term impact of infertility treatment	(-) No details of recruitment strategy (-) No information about content of interview guide (whether there was one) (-) No evidence of self-reflexivity of researcher, discussion of possible biases (-) No discussion of time scale related to stages or what helps people progress through stages, limiting clinical usefulness of findings
Boden, J. (2007) *When IVF Treatment Fails* **England**	To better understand how women and their partners experience infertility and come to terms with childlessness	18 couples and 15 women who had failed cycle of Tx 5 yrs ago	No details of recruitment strategy, participants interviewed in home or at university, data analysis approach was narrative inquiry and thematic analysis	- Most prominent theme was hope, found hope for Tx success carried couples through physical/psychological/emotional stress of Tx, reported struggling to know when to give up Tx - Only 2 out of 33 interviewed had “decided” to remain childless (not considering further Tx or adoption) highlighting need for further research into experience of those who remain childless - Conclude that more counselling support should be offered to patients particularly around ending of treatment	(-) Presentation of findings not very clear, confusing presentation of themes/headings/broad categories which do not offer reader good understanding of key findings (-) Role/bias of researcher who was counsellor at the clinic not discussed (-) Sample not of people who plan to stay childless as was aim of study, therefore limited in ability to answer research aim (how people come to terms with childlessness)
Daniluk (1996) *When treatment fails: The transition to biological childlessness for infertile women* **Canada**	How do infertile women come to terms with and make sense of their experiences of biological childlessness?	37 women who had ‘recently’ abandoned Tx, not clear if any had adopted/planned to adopt	Purposive sampling, recruited through media, support groups, infertility clinics, unstructured interviews, analysed using existential-phenomenological method	- Identified 9 phenomenological themes; sense of futility in continuing, sense of physical/emotional/spiritual depletion, profound loss & grief, sense of emptiness and missed experience, sense of marginalization and envy, desire for closure, sense of needing to redefine self and future, need for acceptance and support from significant others, sense of relief at taking back their lives - Conclude that discussions of acceptance of infertility might be premature if Tx options still exist, results indicate women need to reach own limit when they feel ready to terminate Tx and move on	(+) Reflects on own feminist stance and speaks to feminist therapist reader about possible biases this might create (+) Rich, in depth presentation of themes (+) Offers clear links to practical implications for therapist, key struggles which clients may need support addressing (-) No details of ethical considerations/approval

Daniluk (2001) *Reconstructing Their Lives: A Longitudinal, Qualitative Analysis of the Transition to Biological Childlessness for Infertile Couples* **Canada**	To explore how couples make sense of their infertility and reconstruct their lives when faced with biological childlessness	37 couples, 3 months to 3 years following Tx, by end of study 62% had adopted or awaiting adoption, 38% had "elected to remain childfree"	Purposive sampling, couples recruited through media and infertility clinics. Four semi-structured interviews with each couple over 3 years since stopping treatment, data analysed using phenomenological inquiry	- Identified 4 overall meta themes; 'Hitting the wall', 'Reworking the past', 'Turning towards the future', and 'Renewal and regeneration' - At end of 3 years most well-adjusted, had made active choice about adoption or not having children, those struggling most had lack of closure through awaiting adopted child or undecided about adoption - Make case for potential of counsellors in helping patients to clarify goals for future and re-envision plan for meaningful life w/o biological children	(+) Robust credibility checks, including use of several researchers to analyse and compare interpretations, respondent validation (+) Interviews at 10 month intervals allowed for insight into process over time (+) Large sample (-) No evidence of self-reflexivity of researcher, discussion of possible biases
Johansson & Berg (2005) *Women's experience of childlessness 2 years after the end of in vitro fertilization treatment* **Sweden**	To describe women's experiences of childlessness to help inform care from health professionals	8 women, 2 years post treatment, all childless apart from 1 with foster child	Purposive sampling, recruited through a local public fertility clinic, face to face semi-structured interviews in hospital setting, analysed using phenomenology/'life-world' research	- Describe essence of women's experience 2 years after Tx as 'life-grief', found participants described childlessness as central part of life with many losses, many still hoped for pregnancy, were trying to find other central values in life - Conclude need more research about longer term experiences	(-) 5 of interviews carried out 7 years before rest, only analysed at this time (-) little evidence to substantiate some of claims (-) Lack of clear links with clinical implications (-) No discussion of credibility checks
Lee, Choi, Chan, Chan & Ng (2009) *Life after unsuccessful IVF treatment in an assisted reproduction unit: a qualitative analysis of loss through gains among Chinese persons in Hong Kong* **China**	How Chinese individuals make sense of and attributed meaning to their infertility experience, their losses and gains, and how they reconstruct their lives after unsuccessful IVF Tx	14 participants (10 women and 4 men), last Tx 6 months – 3 years ago, 9 childless, 2 adopted, 2 had conceived naturally	Recruited through sending letters to participants from previous RCT, semi-structured interviews on campus location, analysed using constructivist Grounded Theory	- Although results showed both losses and gains, authors chose to focus on gains in report. Found three common themes among women and men; personal growth, strengthening of relationships and transformational/spiritual growth from experiencing infertility *regardless* of if participant remained childless or not, and this was aided by Chinese spiritual/cultural values around overcoming adversity, surrender and acceptance - Conclude that clinicians should move beyond grief work to consider a strengths based approach and tap into patients' spiritual/cultural values and beliefs	(+) Table showing frequency of particular gains amongst participants increased transparency, credibility of findings (-) No evidence of self reflexivity of researcher, possible biases etc. (-) State choice to present results related to gains rather than losses but do not provide justification for this (+) Provide good rational for new implications for clinical practice
McCarthy (2007) *Women's lived experience of infertility after unsuccessful medical intervention* **USA**	To better understand lived experience of infertility for women in aftermath of unsuccessful medical treatment	22 women, average of 3.9yrs after Tx, some with adopted children	Purposive sampling, recruited through press release in local newspapers in urban area, interviews in participants homes, data analysed using hermeneutic-phenomenological 'caring inquiry' approach	- Findings indicate impact of infertility felt long after treatment ends, life-defining experience which involves existential crisis and need to redefine meaning of one's life - Conclude that health professionals need to pay more attention to long-term spiritual, psychosocial, and emotional impact of infertility in assessing overall health and well-being of infertile women beyond treatment phase	(+) Rich and in-depth descriptions of core themes (-) No description of interview guide or any evidence of researcher reflecting on own biases, influence on data gathering or data analysis process (-) No mention of credibility checks means ability to judge trustworthiness and plausibility of research findings limited (-) Little discussion of how women who adopted differed from those who remained childless (or not)
Peddie, Teijlingen & Bhattacharya (2005) *A qualitative study of women's decision-making at the end of*	To explore women's perception/satisfaction with decision making process to	25 women, 3-24 months since stopping Tx, 2 had adopted, the rest	Purposive sampling, semi-structured interviews, analysed using thematic analysis	- Stopping Tx provided relief from emotional and practical costs of Tx, however many still struggling with uncertainty/doubt about decision, majority expressed still struggling to accept childlessness, those most happy with decision had adopted	(+) Evidence of credibility checks, including use of several researchers (+) Rich descriptions to back up findings (-) Poor definition of terms – describe women having 'not reached point of acceptance of

IVF treatment **Scotland**	end IVF Tx	childless		- Conclude not enough information/support with decision making process from professionals, suggested specific counselling session focused on aiding decision making	childlessness’ but not defining what this might look like
Su & Chen (2006) *Transforming hope: The lived experience of infertile women who terminated treatment after in vitro fertilization failure* **Taiwan**	To explore lived experience of infertile women who terminate treatment after IVF failure	24 women, 1-2 years since stopping Tx, not clear if any had non-biological children	No information about recruitment strategy. Telephone interviews, analysed using interpretive phenomenology	- Identify 3 main themes; accepting the reality of infertility, acknowledging the limitations of treatments, and re-identifying the future which they claim are essential to healing and recovery process - Conclude that health professionals should provide both positive and negative information about treatment not to raise unrealistic hopes about chance of pregnancy	(-) No explanation or details of recruitment strategy (-) Poor evidence of credibility checks (-) No evidence of self reflexivity of researcher (-) Conclusions and clinical recommendations raised in discussion have no clear links with results
Vogsten, Svanberg & Olsson (2010) *Unresolved grief in women and men in Sweden three years after undergoing unsuccessful in vitro fertilization treatment* **Sweden**	To explore the experience of men and women undergoing unsuccessful IVF Tx and of remaining childless 3 years after IVF	10 women and 9 men, 3 years since unsuccessful IVF, no biological children	Recruited through local IVF clinic. Semi structured interviews in hospital setting. Data analysed using content analysis.	- Found most participants were still struggling with feelings of grief 3 years after Tx, but that women reported more symptoms of depression, guilt and low self esteem than men. - Conclude that health professionals involved in offering IVF should make patients aware of possible grief reactions and possible need for support following unsuccessful Tx and more assistance with decisions around ending Tx should be offered	(+) Include sample of both men and women and compare their experiences (-) Researcher known to some participants but no discussion of possible impact of this, little evidence of self-reflexivity (-) Lack of ethnic diversity in sample, only people with Swedish background
Wirberg, Moller, Hogstom, Tronstad & Lalos (2007) *Life 20 years after unsuccessful infertility treatment* **Sweden**	To gain knowledge and insight into long lasting effect of and coping with involuntary childlessness 20 years after fertility Tx	14 women who had undergone tubal surgery 20 years previously, all involuntarily childless	Recruited through hospital records of historical fertility Tx. Semi-structured interviews in place of participant’s choosing. Data analysed using ‘qualitative approach’	- Participants reported childlessness had powerful impact on life (50% reported partner leaving b/c of infertility), but majority (11/14) claimed they had adapted to and accepted childlessness, were satisfied with their lives, and could see advantages to not having children. Were aided by investing in hobbies, work, relationships and finding other parenting/ caring roles - Result showed infertility not one-off crisis, but crisis which comes up again in life cycle (like when not becoming grandparent), highlight need for model of counselling to support self reflection and personal agency	(-) Possible response bias, query if those elected to respond more comfortable/happy with outcome than those who didn’t (-) No information about specific data analysis approach (+) Rich and in-depth descriptions of core themes (-) Poor evidence of credibility checks

1.7.3 The experience of deciding to stop fertility treatment

Only one study identified in the literature review focused specifically on the experience of deciding to stop fertility treatment (Peddie, Teijlingen & Bhattacharya, 2005), whilst two other studies exploring the experience of unsuccessful fertility treatment contributed to understanding in this area. Peddie and colleagues interviewed 25 women in Scotland 3-24 months after abandoning unsuccessful IVF treatment to get a better understanding of the circumstances influencing the decision to end treatment, as well as the women's level of satisfaction with their decision. They described that the decision to stop treatment offered a way out of the multiple emotional and financial stressors of ongoing treatment, but also created a sense of ‘confrontation’ with the reality of their infertility which they felt ill prepared to manage, as many described a sense of ‘false hope’ for success throughout the treatment process. Many participants described feeling disappointed with the final consultation with the clinic as well as the lack of contact and support from the clinic after the end of treatment, which left many feeling unresolved and second guessing their decision. From the results the authors conclude that clinics should offer a dedicated decision making counselling session to create a more clear and personalized discussion about the pros and cons of carrying on with treatment.

Bergart (2000) found very similar results in a smaller American study exploring the experiences of ten women who had recently discontinued unsuccessful fertility treatment. Participants described going into treatment with high hopes that medical intervention would be able to “fix” their infertility, and became easily swept up in the “linear momentum of the technology” (p. 65) trying more and more treatments in hope that the next would be successful. A minority of the participants spoke positively about how their doctor was able to help them exit the cycle of ongoing treatment by looking realistically at the low probability of success and setting limits on treatment. However, the majority said their doctor would have treated them indefinitely, and that this made the decision of when to cease treatment a more difficult and stressful experience.

Boden (2007) interviewed 33 men and women whose treatment had failed 5 years earlier, and found that hope and the wish to prevent regret had been the two main factors motivating participants to carry on with treatment. However, as the author highlights, the boundary between ‘doing enough’ (to have the best chance of success and to pre-empt future regrets) and ‘doing too much’ is indistinct, leading Boden to highlight the importance of more professional input and help for patients with deciding where this line should be drawn. Results showed ambiguity around this decision for many participants 5 years after their last treatment, with the author reporting that approximately 1/3 of participants had made the decision to pursue adoption, a small minority (2/33) had “decided unequivocally to remain childless”, and (evidently) the remaining participants were still unclear about whether or not to pursue further treatment or seek other avenues to parenthood.

1.7.4 The aftermath of stopping unsuccessful treatment

There seems to be consensus across the literature that one of the most central experiences following ending unsuccessful treatment is grief. Vogsten, Svanberg & Olsson (2010) interviewed 19 Swedish men and women 3 years after ending treatment, and summarized their experiences as “unresolved grief”, as the majority of participants reported that they were still processing what they had been through, and did not feel they had adapted to childlessness. Both men and women in the study reported feeling both surprised and unprepared for the grief they felt following the end of treatment, and as such few had sought out any form of professional support with this. Women in the study (more than men) also reported symptoms of depression, including lack of self esteem, feelings of worthlessness, guilt, and blaming oneself for being childless. Another Swedish study (Johansson & Berg, 2005) exploring the experiences of 8 women 2 years after ending treatment found similar results. Based on their interviews, they summarized the central experience of their participants with the concept of ‘life-grief’, which they described as not only the grief of not having a child, but also the loss of being able to carry on one’s family line, and not being able to confirm one’s relationship through parenthood.

McCarthy’s 2007 phenomenological study offers a more in depth investigation into women’s lived experience of infertility after unsuccessful treatment. Based on interviews with 22 American women an average of 3.9 years after treatment, the author highlights that in addition to grief, participants were also faced with an existential crisis of trying to make sense of their identity and the meaning of their lives without biological children and that participants were at different point of resolving these challenges. Based on the results the author concludes that health professionals need to pay more attention to long-term spiritual, psychosocial, and emotional impact of infertility in assessing the overall well-being of women suffering from infertility beyond the treatment phase.

In a 2009 study of 14 Chinese men and women who had stopped unsuccessful fertility treatment 6-months to 3 years previously (Lee, Choi, Chan, Chan & Ng, 2009) participants spoke not only about the losses associated with infertility, but also what they had gained from their experiences. Participants described a sense of personal strength from having survived the struggles of infertility, a strengthening of some of their relationships (with their partners, family and friends who supported them, and with fellow IVF service users), and a sense of spiritual growth through seeking acceptance about the situation, finding ways to make the most of their experience, and from helping others. Another Asian study exploring the experiences of 24 Taiwanese women 1 to 2 years after ending fertility treatment (Su & Chen, 2006) also painted a somewhat more optimistic picture of women's experiences following unsuccessful treatment compared to the other studies identified in the literature review. They reported that overall, participants were able to let go of their hopes for a baby and instead generate a broader feeling of hope for their own life and future without children.

Whilst Su & Chen suggest that traditional Taiwanese cultural values around the role of women were something that their participants had to overcome, Lee and her colleagues highlight how certain Eastern values and beliefs seemed to aid their participants in their ability to find positive meaning in their experiences. For example, many participants made reference to Confucian sayings around people's capacity to overcome adversity, and Buddhist and Daoist beliefs around acceptance and relinquishing control. Based on the findings, the authors conclude that clinicians should move beyond grief work to consider a strengths based approach that taps into patients' spiritual/cultural values and beliefs.

1.7.5 Adjustment over time

A small group of studies have attempted to explore how people adjust to unsuccessful fertility treatment over time. Blenner (1990) interviewed 25 couples at different stages of their journey with infertility treatment, including those about to start treatment, those who were in treatment, and couples who had discontinued unsuccessful treatment. She identified three broad stages that participants progressed through, starting with *engagement* into treatment (which included a dawning of awareness of fertility issues, facing the reality of treatment, and feeling hope and determination that treatment would work), followed by *immersion* into treatment (which included infertility becoming a central focus in life, the deferring of making life plans to a later point, and a 'spiralling down' as treatment was not successful and felt overwhelming), and finally ending with *disengagement* from treatment (which included setting deadlines for the end of treatment, considering other options for parenthood, and shifting focus onto other pursuits in life).

A 1996 study exploring the experiences of 37 Canadian women who had recently abandoned unsuccessful treatment offers a bit more insight into the process of *disengagement* highlighted in Blenner's study (Daniluk, 1996). Through interviews with participants, Daniluk reported that each of the women she spoke to described reaching a "a discrete point when they knew that to move forward and take back their lives" and that "it was only with the abandonment of the pursuit of answers and solutions of their infertility that they began the painful process of letting go of their hopes and dreams, and of coming to terms with the fact that they would likely never bear a child" (p. 92-93). These results seem to offer important insight into the process of disengagement from treatment for two reasons. Firstly, Daniluk reports that for some participants, the point of wanting to end treatment could only be reached once they felt they had thoroughly pursued all possible medical options and felt they had 'left no stone unturned'. These results led the author to conclude that any attempts to discuss acceptance of permanent infertility with someone who is still in treatment is likely to be premature. The second implication of this study is the suggestion of a discreet line separating the period *before* deciding to end treatment, and the period *after* deciding to ending treatment, as the author suggests it is only after discontinuing treatment that women start the work of facing the grief and losses of biological childlessness.

Daniluk (2001) expanded on these findings in a 3 year longitudinal study in Canada, in which couples were interviewed at 10 month intervals starting 2 months after they stopped trying to conceive. Results suggested a progressive adaptation to biological childlessness over time, which the author described in terms of four broad themes corresponding to each 10-month period. In the first period '*hitting the wall'* the author describes participants coming face to face with the reality of permanent infertility, experiencing despair and fear about the future, and withdrawing from others. In the second 10 month period participant experiences were summarized with the theme of '*reworking the past',* as many spent time looking back, and feeling anger and frustration at lost years consumed by treatment. In the final two periods, '*turning toward the future*' and '*renewal and regeneration*', participants were described as starting to re-envision an alternative life path without children, recognise what they had gained through their struggles, and described a greater sense of control over their lives. At the end of the 3 years results indicated that the most well-adjusted couples had made an active decision about parenthood, either by achieving adoption or by making the decision not to have children. In contrast, couples expressing the most distress remained uncertain about their future, either because they were awaiting adoption or because they were still undecided or disagreed as a couple about adoption.

Only one study in the literature review looked at longer term experiences of involuntary childlessness following unsuccessful fertility treatment. Wirtberg, Möller, Hogström, Tronstad & Lalos (2007) interviewed 14 Swedish women who had undergone tubal surgery 20 years previously. Participants described that childlessness had had a powerful impact on their life, leading them to experience low self esteem, feelings of inferiority, social isolation, and (for half of participants) was described as having led to the breakdown of their relationship. Despite this, the majority of participants reported they had regained their self esteem, were satisfied with their lives, and could see advantages to not having children. They described that investing in other areas of life, like work, relationships and hobbies, as well as finding other parenting/ caring roles aided them in the "transition and adaptation to non-parenthood" (p. 603). The results did suggest that many of the women felt thrown back into the feelings of loss and social isolation as many of them reached the point when friends and family were having grandchildren. This led the authors to conclude that adaptation to involuntary childlessness is not a linear process or a one off crisis and that there "is a need of models that contain crisis as a recurring event embedded in the life cycle" (p. 603).

1.7.6 Quality of papers

The Critical Appraisal Skills Programme (CASP) Qualitative Checklist (2017) was used to help judge that quality of the 12 studies identified in the literature review (see Appendix A). CASP checklists are critical appraisal tools originally developed by the Oxford Regional Health Authority to help health professionals make sense of the quality if research in order to ensure medical guidelines are evidence based. The qualitative checklist was developed by a group of experts in the area of qualitative literature and covers 10 key criteria for judging the quality of a piece of research.

A review of each study against the quality checklist showed that the quality of research varied greatly. Only one study (Peddie, Teijlingen & Bhattacharya, 2005) met each of the 10 criteria included in the checklist. Another 5 studies met most of the criteria and seemed to offer largely rigorous and credible research which could make a valuable contribution to the understanding of how women experience moving on from unsuccessful infertility treatment (Daniluk, 1996; Daniluk, 2001; Lee et al. 2009; Vogsten, Svanberg & Olsson, 2010; Wirberg et al., 2007). The remaining 6 studies (Bergart, 2000; Blenner, 1990; Boden, 2007; Johansson & Berg, 2005; McCarthy, 2007; Su & Chen, 2006) had significant limitations to the quality of the research design/data gathering/data analysis which limited their contribution to the evidence base. The most common limitations of the studies were a lack of clarity around sample population (inclusion/exclusion criteria, whether participants were childless or not), lack of self reflexivity of researcher/s, insufficient evidence to support claims, and poor evidence of attempts to assure the credibility of findings.

With the exception of two studies which took place in Asia (Lee et al., 2009; Su & Chen, 2006), the current body of evidence was based almost exclusively on the experience of white, well-educated, heterosexual men and women from Europe and North America. Although this seems characteristic of the demographic profile of those who pursue fertility treatment (Zegers-Hochschild et al. 2014; HFEA, 2013), women from more diverse ethnic, cultural, and socioeconomic backgrounds are clearly underrepresented in the literature. The majority of the studies (8/12) looked exclusively at the experiences of women, while 5/12 interviewed couples. Of the 5 studies which looked at couple’s experiences only one interviewed men and women separately (Vogsten, Svanberg & Olsson, 2010). In line with the quantitative literature (Jordan & Revenson, 1999; Wright, Duchesne & Sabourin, 1991), this study provided more evidence that men and women may indeed experience the transition to involuntary biological childlessness in different ways. This suggests that there may be advantages to further qualitative research which specifically explores either men or women’s experiences, as this type of research may have the potential to offer more insight into the subjective experiences of biological childlessness which might be gender based.

Only one study identified in the review employed a longitudinal design (Daniluk, 2001). The ability of this study to offer insight into women's experiences over time is a strength, as previous research has shown that the women's emotional responses to fertility treatment vary greatly across different stages of treatment and post –treatment (Verkaart, 2007). In contrast, it was a weakness of several studies which stated that participants were 'post treatment', but then did not specify the length of time since stopping treatment (Bergart, 2000; Blenner, 1990; Daniluk, 1996). The remaining cross sectional studies seem to offer a 'snapshot' of women (and men's) experiences at different time points, which together help to form a growing picture of adjustment to unsuccessful treatment over time. Only one study specifically explored the experience of deciding to stop treatment (Peddie, Teijlingen & Bhattacharya, 2005), and again only a single study examined longer term experiences of childlessness following unsuccessful fertility treatment (Wirberg et al., 2007). How people exit the cycle of ongoing treatment, and how they cope long term after doing so are areas of the literature which need further investigation.

A clear methodological weakness across the studies was a lack of self reflexivity of the researchers. With two exceptions (Peddie, Teijlingen & Bhattacharya, 2005; Daniluk, 1996), there was little evidence that researchers had reflected on how their own role, biases or epistemological stance might influence the data gathering process and the claims being made. For example, two researchers stated that they were professionals working in the infertility clinics from which they recruited and known to some of the participants (Boden, 2007; Vogsten, Svanberg & Olsson, 2010), but then did not go on to discuss how this could influence the participants and their own interpretations. In another study (Lee et al., 2009) the researchers stated that they chose to present only the gains associated with unsuccessful fertility treatment reported by participants (and not discuss the reported losses), but failed to justify this subjective decision or discuss how it biases the results.

The majority of the papers identified in this review lacked transparency about the research process, which made it difficult to judge whether or not the data analysis process was sufficiently rigorous to justify claims. There were a few notable exceptions to this (Daniluk, 1996; Daniluk, 2001; Lee et al., 2009; Peddie, Teijlingen & Bhattacharya, 2005) which offered details about the data analysis process, were clear about how themes and categories were derived, and provided sufficient data to support findings. These and two other studies (Vogsten, Svanberg & Olsson, 2010; Wirberg et al., 2007) also provided evidence of credibility checks, like using several researchers to analyze and compare interpretations and respondent validation. The remaining studies made no reference to credibility checks, limiting the trustworthiness of their findings, and therefore their potential contribution to the evidence base.

1.7.7 Summary of research literature and clinical relevance

A review of the literature suggests that women go into fertility treatment with high hopes of success, and that over time, health professionals might contribute to a sense of 'false hope' that treatment will eventually be successful. Reports suggest that the decision of when to abandon treatment is an extremely difficult one, and that many women feel a lack of support and guidance with this. Based on these finding, several authors recommend that health professionals should help patients consider the possibility of treatment failure earlier on (Boden, 2007), that clinics should offer dedicated decision making sessions (Peddie, Teijlingen & Bhattacharya, 2005), and that final sessions should be offered after terminating treatment in order to help establish a sense of closure (Bergart, 2000).

After deciding to abandon unsuccessful treatment, evidence suggests that women experience grief (Vogsten, Svanberg & Olsson, 2010; Johansson & Berg, 2005) as well as existential challenges to their sense of meaning in life (McCarthy, 2008). Other studies highlighted that living through unsuccessful treatment may generate feelings of personal growth and gain (Su & Chen, 2006; Daniluk, 2001). This seems to be a novel finding not reflected in the quantitative literature, and highlights the potential advantages of exploratory approaches which may have the ability to shed light on certain experiences which the use of narrow outcome measure (like depression, anxiety, grief) might fail to capture. Together these studies point to the potential therapeutic advantages of support which addresses not only grief, but also the wider existential challenges (and potential areas of growth) that come along with living through unsuccessful treatment.

With respect to adjusting to unsuccessful treatment, evidence from two of the studies reviewed suggest that the work of facing biological childlessness may only really start once a decision to stop treatment has been made (Daniluk 1996, 2001). After this, it seems women go through a process of grieving, of trying to make sense of what they have been through, and of planning for new versions of the future. This supports quantitative evidence that the most important stressors associated with IVF are coping with treatment failure, and not of coping with the stress of treatment itself (Verhaak et al., 2007a). These findings seem to go against some of the current counselling practices which focus treatment on supporting those still undergoing treatment, and highlights that support may be most needed not during treatment, but after abandoning unsuccessful treatment.

Evidence from the quantitative literature (Verkaart et al., 2007b), and the qualitative literature (Daniluk, 2001) suggests that those who persist in hoping for a biological baby (either through continuing treatment, or by remaining undecided about whether they will return to treatment) express more distress and dissatisfaction compared to those who have ‘moved on’ towards other things (whether this be adoption or other life pursuits). Although this highlights the importance of clear and active decision making around when to stop pursuing treatment, neither the quantitative nor the qualitative literature offers much insight on how women are able to make this decision, and what might help or hinder this process.

1.8 Research aims

This introductory chapter sheds some light on the experiences of a group of women who seem to be poorly understood and rarely heard in both in the public discourse and the research literature. In the UK today, more women are turning to fertility treatments like IVF to help them get pregnant than ever before. Despite public perceptions of the power of medical technology to solve infertility, in reality up to 50% of those seeking fertility treatment will end up biologically childless. A review of the literature exploring women’s lived experience of moving on from unsuccessful fertility treatment offers some insight into the many challenges, and possible gains, of living through this process. However, much of this small body of evidence is of poor methodological quality, and few are designed in a way that results can be generalized. Furthermore, only two studies were carried out in the UK, whilst the remaining studies were conducted in different countries where access to fertility treatments as well as alternate pathways to parenthood often differ significantly, which may conceivably create meaningful differences in how unresolved infertility is experienced. These significant limitations to the evidence base mean that health professionals have little to draw from with respect to how best to support women coping with unsuccessful fertility treatment when they come into contact with health and mental health services. Furthermore, the factors and processes contributing to *how* women are able to exit the cycle of ongoing fertility treatment and let go of their dreams of having a baby to focus on other pursuits is still poorly understood.

In light of the above, the main research aims of this study are:

1. *To gain knowledge and deeper insight into how women experience the decision to abandon unsuccessful fertility treatment*

2. *To generate a better understanding of the psychological process that women go through in transitioning from trying to become pregnant to pursuing a life without biological children of their own*

Chapter 2: Methodology

2.1 Overview

In this chapter I will start by introducing the use of grounded theory for this project and the rational for this. I will explain why individual interviews and a focus group were selected to gather data, and offer details of the recruitment and data gathering process. I will then provide details of the data analysis process, providing examples along the way to help the reader understand how my interpretations and constructions of the data developed over time. Finally, I will describe the steps taken to ensure the quality of this research project, focusing specifically on measures taken to increase the rigour, trustworthiness and credibility of the findings.

2.2 Design

2.2.1 Grounded Theory

A qualitative design using Grounded Theory was used for this study. A qualitative approach was selected for several reasons. Firstly, little quality research has been conducted in the area of moving on from unsuccessful fertility treatment, and although there exists a small body of empirical papers that begin to make sense of this experience, there are no existent theoretical models of how such a process might unfold. Furthermore, research suggesting that women facing treatment failure (and particularly those who struggle to disengage from treatment) are at risk of developing depression and anxiety highlights the need for a better understanding of women's subjective experiences of moving forward from unsuccessful fertility treatment in order to best inform clinical practice. Qualitative approaches allow for this type of inquiry into personal experiences and meanings in a way that quantitative approaches do not.

Grounded theory (GT) is a non-experimental qualitative approach to gathering and analysing data in order to construct a theory 'grounded' in the data (Glaser and Strauss, 1967). It differs from other methodological approaches in its focus on developing new theories directly from the data being gathered, rather than following up preconceived notions in the field or hypothesis testing. This approach seemed particularly well suited to meet the research aims as there was a lack of existing theories in the field about how women move on from unsuccessful fertility treatment, and because GT goes beyond just describing experiences to producing an explanatory theoretical framework about how such a process of adjustment might occur.

GT provides a clear framework for how to approach the gathering and analysis of qualitative data for theory construction, which will be detailed further in the data analysis portion of this chapter. GT also provides broader tenets of how to approach planning a research project, like delaying conducting the full literature review until after data has been gathered and analysed to avoid viewing the data through the lens of existing theories. These and other GT strategies, like memo writing, were employed in this study in the pursuit of building a theory grounded in data.

2.2.2 Consideration of other methods

In the early stages of developing this project, other methodological approaches and data gathering techniques were considered. Discourse, narrative, and interpretative phenomenological analysis (IPA) were all explored as possible approaches to answering the research questions (Silverman, 2013). Each approach offered an interesting take on the topic; IPA presented the opportunity to carry out an in-depth investigation into how women experience and give meaning to unsuccessful infertility and involuntary childlessness, whilst discourse analysis or narrative analysis could help to illuminate how they story these experiences to others, and the social discourses available to them to talk about infertility and childlessness.

Ultimately the questions of clinical relevance helped clarify the choice of GT over other possible approaches. When considering what type of information would be most useful for women experiencing unsuccessful fertility treatment (and the health professionals who support them), a framework for understanding the process of how women are able to move on from treatment seemed most practically useful, rather that solely focusing on the meaning of this process, or how they presented their journey to others. Furthermore, I did not want to only answer *what* factors might contribute to the decision to stop fertility treatment or aid adjustment to involuntary childlessness, but also a model of *how* women were able to exit the cycle of ongoing fertility treatment, and move on when fertility treatment was not successful. GT seemed to be the only approach that had the added value of explanatory power to theorize about how this process occurs.

2.2.3 Focus on women's experiences

The decision to focus this study on women's experiences as opposed to gaining the views of couples was made for several reasons. Firstly, a large body of research evidence has shown that women find infertility and the experience of fertility treatment more stressful and are at higher risk of developing depression, anxiety, and low self esteem compared to their male partners, indicating that men and women may differ in their experience of infertility in important ways (Jordan & Revenson, 1999; Duchesne & Sabourin, 1991; Pasch, Dunkel-Schetter & Christensen, 2002). In keeping with the Grounded Theory principle of theoretical sampling, this decision was reviewed following analysis of the first three interviews. As the analysis thus far was starting to indicate the importance of gender based factors on the experience of moving on from unsuccessful fertility treatment (like links between motherhood and one's identity, and the social stigma of being a childless woman) the decision was made to continue interviewing women individually to further explore these factors.

2.2.4 The use of interviews and a focus group

Semi-structured interviews were chosen as the method of data gathering for this study as it seemed the best way to gain a deeper understanding of participants' beliefs, motivations, and experiences of unsuccessful fertility treatment. Charmaz (2006) talks about a 'good fit' between GT and interviews as a method of data gathering, as interviews provide both the flexibility and the structure to meet the two aims of any GT study, which is both hearing the participant's story as well pursuing theoretical leads and constructing a theory through the data collection process (Charmaz, 2006). A key tenet of the GT approach is the iterative process of going back and forth between data gathering and data analysis, and with interviews it is possible to analyse data from early interviews, identify key themes, and then return to the field to follow up on promising leads and emerging ideas in subsequent interviews.

The decision to carry out a focus group was made after 8 individual interviews had already been conducted and an early version of a theoretical model had been developed. At this stage of the research, I was keen to explore my tentative ideas about the key processes associated with moving on from unsuccessful fertility treatment with new participants. A focus group seemed the best way to do this for several reasons. Firstly, presenting the model to several participants at once would allow for commonalities and differences in participants' experiences to be explored and discussed. Analysis thus far had indicated that the time since stopping fertility treatment seemed to be an important factor influencing participants' perspective on their experiences. Therefore, having several women in one room who were at very different points in their journey with respect to the time since stopping fertility treatment (which ranged from 3 months to 25 years) allowed for further exploration of this theory.

Others (Wilkinson, 1998) have highlighted that a strength of using focus groups is that they allow participants to take greater control over a topic of conversation, and therefore can take some steps towards redressing the power imbalance inherent to the interview process. Furthermore, analysis of the group interaction added an extra layer of information about the social processes surrounding discussing the topic of infertility and childlessness, which could not be achieved by relying solely on individual interviews.

2.3 Ethical considerations

This study was reviewed and approved by the University of Hertfordshire research ethics committee (see Appendix B). An amendment was sought and granted to include the use of a focus group and the help of transcription services (see Appendix C). Ethical practice over the course of research was guided by the Code of Human Research Ethics (British Psychological Society [BPS], 2014) and was carried out in accordance with the Data Protection Act (1998).

All participants expressing interest in the study were sent an information sheet detailing the aims of the study, the potential risks and benefits of participating, and informing them of their right to withdraw from the study should they wish to (see Appendix D). Details were also provided about how anonymity and confidentiality would be maintained, including the removal of any identifiable information, the use of pseudonyms, and the secure storage of data using password protected files. All participants were given time to consider this information and were encouraged to ask questions either via email or by having an informal telephone discussion to clarify any questions or concerns. Several participants took me up on the offer of having a discussion ahead of the interview, and two requested that I send them the interview questions ahead of time. Following reading the information and answering any questions they had, all the participants were still keen to participate. Prior to the interview and focus group, participants were asked to sign a consent form (Appendix E).

Due to the sensitive nature of the topic, measures were taken to ensure participants wellbeing during their involvement in the study. Participants were informed that they were free to take a break during the interview process, skip any questions they did not feel comfortable answering, or terminate the interview all together should they wish. During the focus group, time was taken in the introduction to discuss how difficult emotions could be managed in the group.

Some ethical considerations could not be planned for, but arose over the course of the project. For example, one participant ended up sharing some private information about her partner that she did not want included in her transcript. We spent time talking this through at the end of the interview and agreed exactly which section I would leave out of the transcript, which this participant was happy with. Later on in the research process when I had developed a preliminary model, I arranged an interview with a participant specifically aimed at getting her reflections and interpretations of my understanding so far. In keeping with GT approaches, I had intended this interview to be shorter than my earlier interviews, as I was ‘honing in’ on what I had interpreted to be some key theoretical understandings. When I explained this to the participant, she was clear with me that although she wanted to contribute to the project, she did not only want to talk about the theoretical model. She wanted the opportunity to tell her story, which she shared she had not felt comfortable talking about with friends and family. It felt important in this moment that *my* aims for the interview did not overtake and supersede hers, and that we share the interview space for both our objectives. Ultimately by extending the time of interview and (and by passing along information about support services which this participant had not been aware of), I felt that we succeeded in making the interview something which met both our aims.

A debrief was conducted at the end of each interview and after the focus group in order to give participants space to reflect on what the process had been like for them, how they were left feeling, and whether or not it raised any issues which they wished to seek support with. All participants given a debrief form with details of relevant support organizations should they feel some additional support would be useful (see Appendix F).

2.4 Procedure

2.4.1 Recruiting participants

Participants were recruited online through support forums and Facebook groups for women coping with infertility and involuntary childlessness (see Appendix G for a complete list). A brief study ad was listed on these forums with a link to a website which offered an electronic version of the participant information sheet. Those who visited the website were then asked to complete a series of survey questions to ascertain their eligibility for the study. Inclusion criteria included being a resident of the United Kingdom and being over the age of 18. Participants were also only considered if they did not have any biological children and had stopped fertility treatment longer than three months ago, which was felt to be a sufficiently long time post-treatment to ensure women had decided to permanently stop (rather than postpone) further treatment.

33 women expressed interest in the study by following the study link and completing the online survey. Of these, 11 did not meet the inclusion criteria, and 10 did not respond to subsequent attempts to contact them. A total of 12 women took part in the study (see table 2). 9 of these participants took part in individual interviews, and 3 took part in a focus group.

In keeping with GT’s concept of theoretical sampling, the number and type of participants recruited was partially determined by the emerging theory (as well as practical limitations of the timescale for this project). For example, as the emerging theory served to highlight that the time since treatment seemed to be an important factor in participants' adjustment to involuntary childlessness, women at very different time points since stopping treatment were recruited for the focus group.

The age range of participants was 31–64. The majority were White British, with two participants describing themselves as British Asian. Participants reported having tried a variety of fertility treatments over a range of 1 ½ to 15 years. The amount of time since stopping treatment ranged from as recently as 3 months ago, to 25 years ago. None of the participants had children, either through adoption or through marriage.

Table 4. Participant Information

Participant # and names*	**Age**	**Ethnicity**	**Relationship status**	**Time in Tx (years)**	**Types of Tx**	**Time since last Tx**
1. Patricia	54	White British	Married	4	6x IVF/ICSI	14 yrs
2. Lisa	41	British Asian	Married	5	5x IVF, acupuncture	1 yr
3. Anna	42	White British	Married	2	3x IVF, 2 x frozen embryo transfers, acupuncture	2 yrs
4. Sally	46	White British	Married	5	1x IVF (ICSI), acupuncture, fertility tests and operations	7 yrs
5. Karen	41	White British	Married	6	2x IVF, Clomid	6 yrs
6. Mary	49	White British	Married	4	2x IVF	12 yrs
7. Jennifer	39	White British	Married	15	Medication, surgery	8 yrs
8. Kate	34	White British	Married	7	4x IVF, 3 x IUI, 6 x Clomid	3 yrs
9. Sue	53	White British	Divorced	4	5x IVF, surgery	15 yrs
10. Beth	39	White British	Married	1.5	3x IVF	3 months

11. Molly	61	White British	Married	10	5x IVF, Clomophine & other drugs, artificial insemination	25 yrs
12. Lucy	38	British Asian	Married	6	ICSI and DI (Donor Insemination)	6 months

*Names have been changed to preserve anonymity

2.4.2 Evolution of the interview guide

A flexible interview guide was developed based on the research aims (see Appendix J). Attempts were made to minimize the chances of preconceiving the data by conducting the full literature review after the data analysis was complete. The interview questions did not aim to ‘check out’ prior theories in the research literature with participants, but rather offer open-ended prompts which would allow me to (initially) gain a broad view of the key aspects of participants’ experience before honing in on key concepts and categories.

The interview guide evolved and changed over time as the study progressed. An early draft of the questions was analysed and re-worked with my research supervisor in an attempt to weed out implicit hypotheses imbedded in the questions. A clinical psychologist working in the field of infertility also reviewed an early draft of the interview guide and gave advice about how questions might be received, and changes were made to ensure that questions were sensitive and not offensive. A researcher who had recently conducted a related study exploring women’s resilience whilst experiencing repeated failed fertility treatment cycles (Bailey, Ellis-Caird & Croft, 2017) also offered feedback on the interview guide. This prompted me to add further questions about what made the decision to end treatment ‘final’ amongst the women I was interviewing, and different from the breaks from treatment her participants had reported.

A pilot interview was conducted with a participant who also worked in the area of supporting childless women, and therefore seemed well placed to offer feedback about the interview guide and process. She highlighted that participants may likely feel curious about my motivation for conducting this study. Therefore, instead of simply asking if they had any questions for me at the end of the interview as originally planned, I asked subsequent participants whether they would find it helpful to hear a little bit about me and why I was conducting this research at the start of each interview. I found that participants were indeed keen to hear this information, and I got the sense that many were interested in whether my interest in the topic came from personal experience of infertility or not. I felt it was important to be open and honest about this, and I shared with participants a bit about me (that I did not have personal experience of fertility treatment, and that I do not have children) and that my motivation for the project came more from a desire to extend knowledge in my field.

Over the course of the interviews, patterns began to be constructed which I wanted to follow up in more detail in subsequent interviews. As such, certain questions were dropped off the interview guide, and others were added or expanded on in order to follow threads picked up from earlier interviews. For example, the themes of social exclusion and being an ‘outsider’ was something several women had spoken about the first few interviews I conducted. After ‘memo-ing’ around this theme and discussing it with my research supervisor, I decided to start asking women about this more directly, which had not been part of my interview guide previously. Asking women about their history of feeling like an outsider in their earlier lives led to some of the most emotionally poignant moments in all of the interviews. This in turn led me to feel more justified in including this question in the interview guide as a clearer theoretical direction for subsequent data gathering began to take shape.

2.4.3 The interview process

All participants were sent a brief survey prior to the interview which asked about demographic information and details about their past fertility treatment (see Appendix I). This allowed participants to share some of the more factual information about their journey with fertility treatment, leaving more space and time in the interview to move beyond this to the emotional and psychological impact of these experiences. Participants were given the choice of conducting the interview face to face, over to the telephone, or via Skype. Three participants were interviewed face to face, two in their homes and one on campus at the researcher’s university. Four interviews were conducted over the phone, and two were held over Skype. Interviews lasted between 45 and 85 minutes.

At the start of each interview participants were asked if they had any questions or concerns about their participation in the study. I offered to speak a bit about why I was conducting the study which all participants expressed interest in hearing about. Participants were reminded of the planned duration of the interview and that the interview could be paused or stopped altogether at any time. Participants were also reminded of their right to withdraw from the study should the change their mind about being part of it.

At the end of each interview, participants were given an opportunity to discuss the process of the interview and asked if they had any further questions about confidentiality or dissemination of the research. I offered to send a copy of the final research article when it was completed, which all participants said they would like to receive. All interviews were audio recorded and subsequently transcribed.

Following the interviews, I took the opportunity to reflect on the content and the process of the interview by writing memos and entries in my research diary. These entries served as important moments of reflection about unspoken elements of the interview process, and what I brought to these exchanges. For example, following the first two interviews I began to sense that participants were giving an overly positive account of their experiences since stopping fertility treatment. After listening to recordings of these interviews, I noticed that I also seemed to be colluding with this, keenly reinforcing messages about the advantages of life without children. In contrast, listening to another interview I noticed I had not really registered or followed up on a comment a participant made about some of the more ‘negative’ aspect of her experiences, like feeling envy and ill-will towards others with children. Charmaz (2014) has written about this phenomenon, and that interviewers may “*unwittingly indicate to their participants which stories are safe to tell and which they cannot bear to hear*” (p. 81). Discussing this with my research supervisor helped me to reflect on how my own personal agenda could be influencing the kinds of stories participants felt prepared to tell me. For example, I reflected that I probably did have a wish that my research would reveal that these women were “ok”, and that the story of how women cope with unsuccessful treatment had a happy ending. Also, I recognized that I was starting to feel very protective over participants, particularly after I gained a sense that many felt judged and misunderstood by others. Bringing this into my awareness and thinking it through helped me to consider how I might be influencing the interviews, which in turn led me to adapt a few of my interview questions to ensure that a fuller portrayal of life following unsuccessful fertility treatment could be told and heard (see Appendix J for a sample of research diary).

2.4.4 Focus group process

In advance of the focus group, all participants were sent both the survey, information sheet, consent form and a preliminary draft of the theoretical model. Some brief information about what to expect from the focus group was also included, and participants were invited to raise any questions or concerns about their participation. The focus group was held in a private room in a venue used for lectures and community events. Once all the participants arrived, a brief introduction was made about the study, about myself, and about the aims of the focus group. Ground rules for the group were discussed and agreed, including confidentiality, creating a safe space in which different points of view were respected, and how difficult emotions might be managed. Some flexible questions prompting participants about their views on the model were prepared and used, but largely the conversation flowed naturally and was led by the participants. The focus group lasted 90 minutes and ended with a debrief exploring how participants found the process of being part of a focus group. Both the interview participants and the focus group participants described some version of the statement "talking helps" when I asked them how they found the process of taking part in the study. It was interesting to note that during the debrief of the focus group, participants also made a point of highlighting that talking with other women who *felt the same as they did* was what they found most valuable about being part of the focus group. Reflecting on this feedback about the process of being part of the focus group added another layer to my understanding of the role of peer support in coping with involuntary childlessness.

2.5 Data analysis

The data was analyzed following the principles and guidelines for GT outlined by Urquhart (2013) and Charmaz (2014). The computer programme QSR NVIVO 7 was used to facilitate the data analysis process. The key aspects of the analysis process are summarized below.

1. Initial coding: The first three interviews were analysed using line by line coding. This type of coding involves fragmenting the data into short segments, and ‘coding’ each segment with a label which aims to summarize the essence of each piece of data. Codes at this stage aim to start to make analytic sense of what is happening in the data, but these interpretations must also stay closely grounded in the text to avoid making pre-mature theoretical leaps. The aim of this initial stage of coding is to do a close reading of *all* the data in order to remain open to all the possible theoretical directions indicated by the data analysis thus far. (See Appendix K sample of initial line by line coding).

2. Focused coding: The next stage of analysis involved pin pointing the most frequent and most significant codes that were constructed during the line by line coding of the first three interviews. These ‘focused codes’ were then used to analyse subsequent interviews and the focus group. This process served to test out the adequacy of my focused codes to account for larger segments of data gathered from subsequent interviews. At this stage many codes were refined, re-worded, or merged together with the benefit of additional data and an emerging understanding of what was happening in the data. For example, ‘*reaching a limit’* ‘*drawing a line in the sand’* and *‘realizing there is more to life’* are all examples of initial codes which were selected as focused codes, as these concepts came up several times in early interviews, and seemed to go beyond descriptive summaries of what participants had stated, but rather started to capture something about the process they had been through.

3. Defining categories and subcategories: Focused codes were then synthesized into tentative conceptual categories and subcategories. This involved the process of looking at how focused codes clustered together under a higher conceptual description which began to capture what was happening in the data. This stage of the process was aided by the use of NVivo which allowed me to pull focused codes together into clusters which appeared to me to have something in common on a conceptual level (see Appendix L for an example of such ‘clusters’ of focused codes). At this stage certain focused codes which seemed to the power to illuminate a key idea or process in a few words were ‘elevated’ to the status of category or subcategory. For example, one participant used the words “*chasing the dream*” to describe the period in her life

whilst undergoing fertility treatment. This seemed to really capture a concept that other participants had described, and was elevated to the level of 'category'. In other cases, a new name was developed which aimed to capture a theoretical description of the data.

4. Theoretical coding: This stage of data analysis involved exploring and describing how categories related to one another on a theoretical level, or a Glaser summarises it, the point at which you "weave the fractured story back together" (1978, p.78). This move 'up' to a higher theoretical level was aided by memo-writing, in which I started to explore hypotheses about the *process* of deciding to stop treatment and adjusting to involuntary childlessness over time. At this point I went back to transcripts of interviews to check out whether these theoretical links did a good job at explaining the similarities or differences between participants, as theoretical codes aim to explain under what conditions certain phenomena occur, or the order things seem to take place in (Charmaz, 2014). The process of clarifying how categories fit together was also aided by drawing diagrams of the emerging theoretical model, of which there was several drafts (see Appendix M for an example of a preliminary model). A table of the categories and subcategories making up the final model are included in Appendix N.

5. Memo writing: Memo writing was utilized at each and every stage of data analysis. Writing memos (informal analytic notes) is a cornerstone of the GT process, and encourages the researcher to take a break from data analysis to clarify and record their emerging ideas, questions, and hunches about the data. Memos helped guide the direction of the theoretical analysis of the data and, together, serve a data trail of the emerging theories and constructs developed over the course of this study (see Appendix O for a sample).

Once a draft of a theoretical model had been developed, a further interview and a focus group was carried out to check out whether or not the categories were able to adequately capture participants' experiences. As this data did not generate any *new* theoretical leads, it was felt that the categories were approaching theoretical saturation, and the process of data gathering came to an end (Glaser & Strauss, 1967).

2.6 Quality assurance

As others have highlighted (Yardley, 2014), the measures used to judge the quality of quantitative research (like objectivity, reliability and statistical generalizability), are less useful when applied to qualitative research. Therefore, qualitative researchers have developed their own guidelines for how to recognize ‘good quality’ research, and aid consumers of qualitative research in judging whether a study’s design is sound and rigorous, and if the findings of a study can be viewed as trustworthy and useful.

Tracy (2010) provides one such framework, and presents eight criteria for evaluating the quality of qualitative research; worthy topic, rich rigor, sincerity, credibility, resonance, significant contribution, ethics and meaningful coherence. In order to thoroughly judge this study based on these criteria, a table detailing the measures taken to meet these criteria, along with examples, has been included in the appendix (see Appendix P). Quality criteria pertaining to the rigor, sincerity, and credibility of this study will be addressed in more detail here.

2.6.1 Rich rigor

Tracy describes that high quality qualitative research is characterized by ‘rich rigor’, which she conceptualizes as having both sufficient richness and abundance of data, as well as evidence of a researcher’s “due diligence, exercising appropriate time, effort, care, and thoroughness” to support their claims (p. 841). The measures taken to ensure an abundance of rich data for this study included carrying out 9 in-depth interviews as well as a focus group with participants with a variety of different experiences with fertility treatment. Furthermore, an attempt has been made to show the care and practice contributed to the data collection and analysis procedure by documenting this process throughout this chapter, by keeping a research diary and memos to document thorough and thoughtful reflections about the data (see Appendix J, O), and by providing a data trail to substantiate claims (see Appendix K-N).

2.6.2 Sincerity

Tracy talks about striving for *sincerity* in qualitative research through two key practices; self-reflexivity and transparency.

Rather than seeking objectivity or trying to take oneself out of the research, self-reflexivity is about the ability to be self-aware of one's own subjectivity, biases, and possible influence on participants and the data they provide. For example, I acknowledge that despite attempts to reduce that chances of forcing preconceived ideas and theories on the data by delaying carrying out the literature review, I did not come to this topic without any knowledge, ideas or expectations about what I might find. Instead of trying to ignore or eradicate these preconceptions, it was my aim to continuously reflect on what these biases might be and how they might influence what I looked for and what I saw in the data. Indeed, as one grounded theorist aptly put it "there is a difference between an open mind and an empty head" (Dey, 1993, p. 63, quoted in Strauss & Corbin, 1998, p. 47). This type of self-reflexivity was carried out at each stage of the research process by keeping a reflective research diary, and through regular discussions with my research supervisor about my subjective feelings and points of view on the emerging analysis.

Sincerity of research also involves being transparent and honest about the data collection and data analysis process. Transparency has been sought in this study by keeping a detailed research diary and records of memos which provide a chronology of the research process, and document the evolution of the theory (see Appendix J, O). Furthermore, the development of codes and categories from the original data have been documented (see Appendix K-N).

2.6.3 Credibility

Credibility refers to the trustworthiness and plausibility of the research findings. From a social constructionist point of view, all research will be based on a subjective interpretation by the researcher, as the aim is not to discover the truth but to explore a co-construction of experience. However, the credibility of this interpretation can still be judged based on the measures taken by the research to avoid misinterpreting the data or making unjustified leaps with the data analysis.

Several such measures were taken to in this study. Firstly, what Tracy calls ‘thick descriptions’ of the data have been provided throughout the write up, including a liberal use of direct quotations in the results, and samples of transcripts, memos and data codes to ‘back up’ the claims of this study. Examples of coded text were shared and discussed with my research supervisor, and a section of an early transcript was line-by-line coded by a fellow GT researcher to compare and explore differences in coding patterns.

Carrying out individual interviews as well as a focus group provided another strategy for increasing the credibility of this research, as it produced different types of data through which to better understand to the process of moving on from unsuccessful fertility treatment. This strategy of employing various methods in order to view a phenomenon through different ‘lenses’ closely aligns the concept of *crystallization* (Ellingson, 2009). Unlike the idea of triangulation from a positivist framework, the aim of gathering multiple types of data is not to help the research get at a more ‘valid’ singular truth, but rather to “open up a more complex, in-depth, *but still thoroughly partial*, understanding of the issue” (Tracy, 2010, p. 843).

Throughout the research process, I sought ‘member reflections’ by asking participants to comment on my interpretations and theoretical understandings so far, both through the interviews and by presenting a preliminary model to a focus group. As Tracy highlights, member reflections differ from the ‘member checks’ often used in positivist research which aim to check with participants whether the researcher ‘got it right’ and discovered the ‘real truth’. Instead, the aim of these discussions with participants was to elaborate and deepen my research findings, rather than test them.

Chapter 3: Results

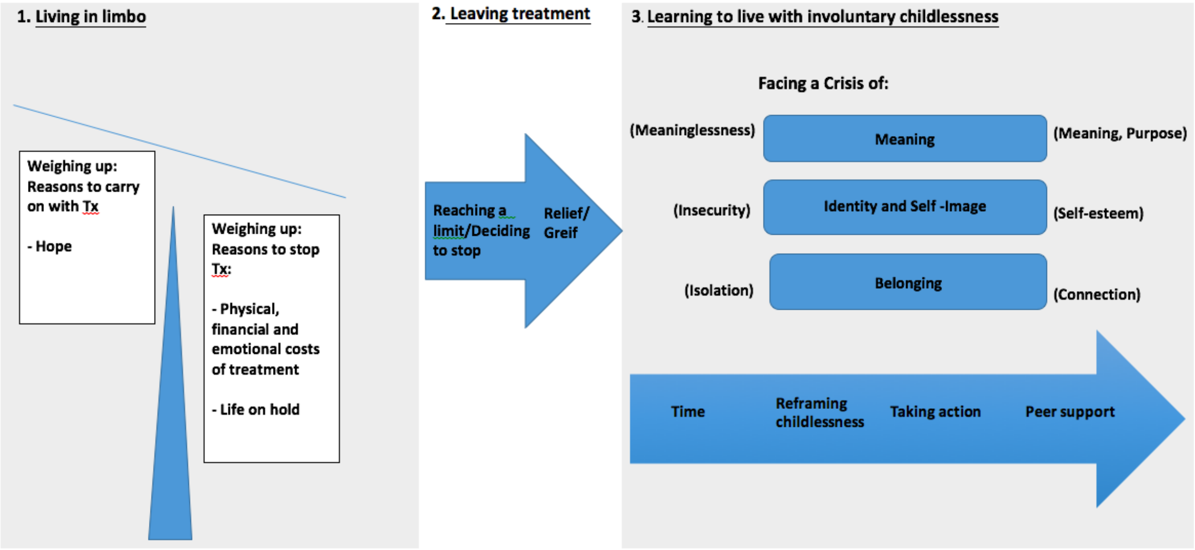
> *"This is not the end. It is not even the beginning of the end. But it is, perhaps, the end of the beginning."*
>
> *- Winston Churchill*

3.1 Overview

In this chapter I will present the findings generated in this study. I will start my introducing the reader to the grounded theory model I have developed. This model was developed in collaboration with participants, and represents a co- constructed understanding of participants' journey of moving on from unsuccessful fertility treatment. After presenting the model as a whole, I will then go on to describe the individual categories representing different elements of process depicted below. I will use quotations from participants to illustrate this process along the way.

3.2 Introduction to model

Figure 2. The process of moving on from unsuccessful fertility treatment



This model illustrates the journey taken by women moving on from unsuccessful fertility treatment. The first box, entitled ‘Living in limbo’, represents the period of life whilst still pursuing fertility treatment. Within this box is a scale representing factors which motivated participants to carry on with treatment on the left side, and factors which contributed to wanting to stop pursing further treatment on the right. The scales represent the weighing out and deliberating that participants did whilst undergoing several rounds of fertility treatment over many years.

‘Reaching a limit/deciding to stop’ depicts participants’ experience of reaching a breaking point where they could no longer carry on with treatment, and decided to stop pursuing parenthood through fertility treatment. This also represents an exit from one phase of life ‘Living in Limbo’, into another phase ‘Learning to live with involuntary childlessness’.

As participants grappled with involuntary childlessness, they faced a series of threats to their sense of meaning and purpose in life, their sense of identity and self-image, and their feeling of belonging and connection to others. Each of these tasks has two points, the left side representing the crisis point, and the right side representing the resolution point to each crisis. Participants’ ability to resolve the challenges which involuntary childlessness raise are represented by the ability to move from the left to the right side of these poles. The bottom arrow represents key mediating factors which aid this process.

3.3 Detailed data analysis

Each part of the model has a number from one to three next to it. This refers to membership of one of three over-arching categories. Each of these over-arching categories, and the subcategories within them, will be explored in greater detail below. Further details of each category are included in Appendix N.

1. Living in limbo
    - Weighing up: hope
    - Weighing up: reasons to stop treatment

2. Leaving treatment
    - Reaching a limit/deciding to stop
    - Dream dying, loss hitting

3. Learning to live with involuntary childlessness
    - Facing a crisis of meaning, identity and belonging
    - Resolution: Finding a way to live

3.4 Living in limbo

Participants spent between two and fifteen years trying different types of fertility treatment in their pursuit of having a baby. They spoke about hope, one the one hand, spurring them on to pursue more and different types of treatment. On the other hand, mounting emotional, physical and financial costs of treatments were described as factors discouraging further treatment.

3.4.1 Weighing up: Hope

Participants described holding onto hope before each treatment, as well as their renewed optimism and excitement each time a new treatment option was considered, like Jennifer who described when surrogacy emerged as a possible solution:

> *For the first time in my life...erm...I...I could almost smell what it would be like to be a mum, taste it. Taste it - that sounds wrong! And I remember going with her looking at prams and my heart going 'oh my god this could be me next year' - Jennifer*
>
> *When you're doing it you believe whole heartedly that it will work – Lisa*

Several participants spoke about each round of treatment as another chance at realizing their dream to have a baby, which was further spurred on by media reports and success stories on online forums;

> *You know you look and someone has tried this and they've got pregnant, and you think oh should I try that? So there is always things being thrown at you that other people have tried that have worked - Anna*
>
> *…(Even) if it's a one in a hundred chance you might win that lottery ticket…I think I thought I would just carry on and eventually surely you've got to…..(*trails off*). There's always someone on the telly who wins on the 85th go. - Sue*

3.4.2 Weighing up: reasons to stop treatment

Emotional, physical, financial costs of treatment

In contrast to the hope they felt before each treatment, participants described feeling devastated when a treatment failed. Several participants spoke about a failed treatment like a bereavement, and described that they grieved for their loss.

> *The first round of IVF hit me hard. It was the whole grieving process – Lucy*

For some participants, fertility treatment did lead to pregnancy, but then ultimately ended in miscarriage.

> *They said 'Ooh look, show her the thing [scan] ... show mum'. They called me 'mum'. And then they said you need to come back in a week or two for the... um, a scan, a proper scan, and then, that's when they found they couldn't see a heartbeat. And that's when they told me it had died, and that stuff. That was the worst, the worst of the whole journey really. – Sally*

In addition to the emotional toll of living through repeated cycles of hope and disappointment, participants also described the physical impact of ongoing treatment on their body.

> *After the last four I felt quite physically unwell, and I kind of felt like what am I doing? What am I doing to my body really? - Anna*

The majority of participants paid privately for some or all of their treatment, either because they had already exhausted the number of free treatment rounds under the NHS, did not qualify for free treatment, or wanted to avoid long waiting lists for treatment under the NHS. The cost of treatment was described as a significant factor in considering whether or not to carry on with treatment, with some participants sharing that they were forced to borrow money from family to cover the cost of treatment.

> *We got some money from my dad, and we paid some, and mummy gave us some money, and that was quite heart wrenching. You know...we wanted to do it ourselves but we weren't that financially...we're just not rich people really.* - Karen

Treatment costs left several participants in debt, which lead some to question their ability to afford the cost of having a child.

> *Even if you have a child, so then how are you going to be able to afford to bring up the child, if you've got all this debt hanging over you, you know?* - *Sally*

Life on hold

Participants spoke about the all consuming nature of being in treatment, and the way that it dominated their lives and left little time or psychological space to focus on other things. Many spoke about being constantly aware of what stage of their ovulation cycle they were in, and planning their schedules around peak fertility times. Others spoke about the restrictions that treatment placed on them, like being advised not to drink or exercise.

> *Everything that I enjoy doing I had to stop. My life stopped.* – Lisa

Participants also described how the uncertainty of whether or not treatment would work made it difficult to plan for the future. Big decisions about one's career, housing and travel were deferred as participants were not sure whether they would soon be pregnant and organizing their life around a baby, or not.

> *You have to put your life on hold. You can't even think about...you can't even plan a holiday...for any long time in the future because you don't know what's going to happen.* – Anna

3.5 Leaving treatment

Although all the participants interviewed in this study stated they had stopped pursuing fertility treatment for good, how and at what point they made this decision (and how much choice they had in the matter) varied according to personal circumstances. For example, for some financial constraints meant they could not pay for further treatment, whilst another participant's severe endometriosis meant she was forced to undergo a hysterectomy. For most participants, it could be said that other options to achieve parenthood (however remote or costly) did exist, however they described reaching a point where persisting with different treatments and solutions no longer felt feasible. Further details of reaching this limit, and the emotional consequences of this, are described below.

3.5.1 Reaching a limit/deciding to stop

Participants spoke about reaching a point when the mounting physical, financial and emotional costs of treatment felt too much, leaving them feeling depleted and unable to face further treatment. Ongoing treatment failures and discouraging prognoses from fertility doctors also left many participants feeling hopeless that further treatment would be successful. Many seemed to reach a tipping point where the costs outweighed the hope for success, and they decided to stop treatment.

> *Even though you're thinking, oh this isn't going to work, still when you go into it the hope goes up again…you just can't help it, and that is really stressful, and it gets more stressful with each one, and that's why after 3 I just knew, I couldn't really face doing it again – Beth*

> *We had had had enough, emotionally, physically, we were... and it wasn't like I was nearly pregnant, it wasn't getting better it was just the same every time - Patricia*

Participants differed with respect to *when* along their journey with fertility treatment they reached this tipping point, with some describing going through up to 6 rounds of IVF before they felt ready to stop, while others described knowing they could not carry on after one round. Approximately half of the participants also described that they reached this point at a different time to their partners, with some stating that their partners felt ready to terminate treatment before they did, whilst others felt some pressure from their partners to carry on. This added an extra layer of stress and complexity to the decision making process, and many participants described a long period of negotiation, debate, as well as conflict about when to stop treatment.

> *We would have the conversation, I would say I didn't want to do it. We would leave the conversation for a bit and then I would just see this dreadful sadness. …So I would be like, oh I was quite excited because I was getting on with my life. But he just looked so sad. So he was never forceful but he looked so sad and it felt like we were in two very different places. - Lisa*

> *My partner felt that unless they fix your endometriosis then there's no point in going through another round. He was also quite worried about you know... the psychological impact on me because he's seen me so upset. - Anna*

Related to the debate about when to stop treatment was also discussions about alternative paths to parenthood, like fostering and adoption. Whilst some participants described being in agreement with their partners about this, others described the tension it created when one partner wanted to adopt or foster but the other did not.

> *We then went through quite a difficult few months erm...where I looked at, was I going to leave? Did I want to be a mum more than I wanted to be with him? …and then I don't know what snapped me out of it but I just all of a sudden I just kind of felt this...that I belong with him and I love him and we had fought so hard to keep what we had. And he'd been so amazing when I was ill that it was then a joint decision that we wouldn't go through with adoption. - Jennifer*

> *I suppose I knew in the back of my mind that he didn't want to adopt, that he didn't want to foster. I looked up some meetings and he wasn't that interested, and you can't go into something like that if you're not 100% - Mary*

To what extent the decision to stop pursuing further treatment represented a distinct moment or a general time period also varied amongst participants. When asked, some participants could point to a specific conversation or moment when they decided to 'draw a line in the sand'. Many of these participants described drawing on concrete markers to help them do this, like setting a limit of three rounds of IVF, or stopping when they turned 40. For others, the process of deciding to stop pursing seemed to unfold over time.

> *Once I got to 40 I was like 'that's it' - Lisa*
>
> *I suppose it probably wasn't like a definite decision after that last course to stop, it was kind of like something gradually over time, I just kept putting off, putting off, putting off - Anna*

Participants spoke about feeling a sense of relief after making the decision not to carry on with further treatment. Many described feeling a weight had been lifted off their shoulders, as they no longer had to cope with the stress and uncertainty of ongoing treatment. Stopping treatment was also described as an opportunity to start living again, and suggested a sense of moving forward after a long period of standing still.

> *It's almost like being free, in a sense….you're being given permission to not have to think about it anymore and get on with life really. – Sally*
>
> *I just got the point where I thought, I don't want my life to be on hold anymore. I want to live life even if it's not a life as a mother…it would still be a life, I can move forward. - Beth*

In contrast to this sense of moving forward, participants spoke about considering returning to treatment as a move 'backwards' into a cycle of hope and disappointment that they were not sure they could cope with again.

> *If you're starting to go through the process of grieving and trying to...(sigh).... establish a new life without this dream. And it's like taking a step backwards to try something else again, and then it fails. It's quite scary... to think – 'oh god, how am I going to feel then!?' – Anna*

3.5.2 Dream dying, loss hitting

Although stopping treatment seemed to offer many participants a sense of relief about no longer having to cope with treatment, interviews also indicated that this was an extremely difficult and painful time in their journey with infertility. It seemed as though stopping treatment brought participants face to face with the reality that their hopes for a biological baby had come to an end, and many reported a deep sense of sadness and loss.

The words of two participants about the moment they realized their hopes and plans for a baby had come to an end captures these common sentiments;

> *And we thought, by having them put back, if it didn't work, we should just get on with our lives, and it would be fine... Very, very matter of fact about it. But actually, when it didn't work, and that was it, because we had decided that was it, erm, it was enough…. the emotional impact of that was quite, well… horrendous - Kate*
>
> *I guess at that point my life and my reality that I had been chasing had just kind of disappeared ... erm ... and…I'll never get over, the sheer weight of that feeling, when that kind of hit me - Jennifer*

Several participants spoke about the period after stopping treatment as difficult time of 'just getting through'. One participant said she 'hibernated' for about a year, whilst others described a time of sitting with the loss, and not yet making plans for the future;

> *We were just getting through. just getting through day to day was enough, just to manage. you know. I wasn't even thinking 'what next?' at that stage it was getting through - Karin*
>
> *I just needed just to be. And um… I had a really dark time from that September up to Christmas - Kate*

It was interesting to note that few used the words "grief" or "mourning" to describe their experiences at this time, although it was my impression that this was what they were describing. Some participants commented specifically that it was only later in life that they looked back and recognized they may have been grieving;

> *I didn't realize it was grief, so I just carried on – Patricia*

Another participant commented on the stark contrast between what she was feeling inside and how invisible this loss was to others around her, leading to a lack of acknowledgement and validation for her loss;

> *I feel like it's a hidden death. And people haven't… you've got nothing to show for it. You haven't had a successful…you haven't even had the little blue line on the stick, so you haven't even told one friends that you're pregnant who can then say, oh I'm really sorry you had that miscarriage - Sue*

3.6 Facing a threat to meaning, identity and belonging

Although participants described a sense of liberation from the pain and uncertainty of ongoing treatment, moving on from treatment also meant taking steps towards living a life they had not planned or expected for themselves; a life without a child and life not being a parent. It should be noted that a minority of the participants did pursue adoption following stopping fertility treatment, but this was not successful in either of their cases. For the two participants who did seek out adoption it was only after all avenues towards their goal of becoming a parent were closed off that they reached the phase discussed in this section, which details the challenges participants faced in pursuing a life without children.

As described in the section above, many participants described the months and even year after ending treatment as a period of sitting with their loss, after which many participants described reaching a point of looking towards the future and of thinking '*now what*?'. The process of facing a future without a child seemed to raise several fundamental questions for participants, which I have conceptualized as posing a threat to one's sense of meaning, self image and sense of belonging. All participants described facing these questions, and all participants appeared to need to to work through these questions in order to find resolution.

> What meaning, purpose and value does my life have if it is not to raise children?
> (Threat to sense of meaning and purpose)
>
> What does it mean for my identity and self image not to be a mother?
> (Threat to sense of identity and self image)

> What does it mean for my social relationships and connections with others not to have children?
> (Threat to sense of belonging and connection to others)

Although I think these three ‘questions’ are deeply interlinked, there do appear to be distinct aspects to them which has led me to present each one separately. Interviews indicated that participants were grappling with these crises to different degrees, with some just starting to ask these questions, and others finding answers to them. I will now present each of these questions in turn, before moving on to the the mediating factors which seemed to influence participants’ ability to resolve these threats.

3.6.1 What meaning, purpose and value does my life have if it is not to raise children?

Several participants spoke about how stopping fertility treatment and abandoning their dreams for biological children forced them to question the purpose of their life. They described that having children had always been their plan, and that the end of this plan left them questioning how they would give meaning to their everyday lives.

> *Sometimes I do wonder if I don’t have children, what my purpose in life is? Erm…what can I do? Cause children give you a purpose, they give you a routine, a reason for living, working and everything…I am a bit fearful of finding that purpose again – Lucy*

Others described a kind of existential crisis of meaning of their lives as a whole;

> *How will I make an impact on the world? You know, leave my legacy? You know you leave it with a family tree, and I'm going to be the end of that – Karen*

During the focus group, Beth (who had just finished her last attempt at IVF three months previously) spoke about questioning the purpose of her life since stopping treatment;

> *This question here about identity and purpose (pointing to the model), is like the first question that I’m…I’m struggling with that question of who am I if I’m not a mother? And I’ve thought about that a lot, and I think I’m somewhere along the*

> *road of thinking about that but I don't have the answer to what the meaning of my life is if it's not to bring up children… I think I'll get there, but I don't know what the answer is yet. (looking to group)…So I don't know how that's been for you? - Beth*
>
> *I would say I still struggle with that sometimes - Sue*
>
> *I think I do - Molly*

Molly and Sue's response that they still struggled with this question 15 and 25 years after ending treatment indicated to me that questions of meaning and purpose are perhaps not something that have a definitive "answer" like Beth was describing. Instead, Sue's statement that the struggles with this "sometimes" seems to suggest that when living with childlessness, this anxiety and questioning about the purpose of one's life might be re-triggered and re-emerge at different points.

When discussing meaning and purpose, several participants spoke about how their lives were seen by other people. It seemed like the underlying assumption was that society viewed their life as less valuable and less meaningful than a life as a parent. As such, the measure of a 'good life' seemed to be measured by creating a life that others would view as valuable, and perhaps even envy;

> *I feel like for us we need to do something drastic, we need to do something crazy, we need to do something out there. Maybe to prove, there is more to life than having children…and try to justify it to others. – Lucy*
>
> *I'm probably almost trying to imagine saying to people in a few years time about other things that I'm doing...people might, I mean where I might envy them for having children, they might envy ....think 'Oh -she has a really good life now'. Erm...so yeah, that would be a nice place to get to – Anna*

Interviews also indicated that not being able to have children threatened participants' beliefs about meaning and purpose in the world, as many described grappling with the logic and meaning of why they were not able to have children, while others around them could. For many this led to feelings of injustice and unfairness, and seemed to threaten their beliefs about justice in the world, like the idea that hard work is rewarded, and that good things happened to good people.

> *When someone who dies, a family member or someone close....like with my mum as she was getting older and getting ill, I can justify that, I can understand that. That she died because she was ill. Whereas I can't explain and accept why I'm not a mother. – Mary*

> *I was kind of... always the good girl? I was somebody who worked hard, and, you know, not... you know would take any opportunity, never been given anything, so we kind of... we felt like it was really unfair. – Kate*

The implication here that "good" girls have babies seems to speak to social constructs of fertility as good and infertility or childlessness as bad. This statement could also be linked to historical ideas of infertility as a punishment for being bad, which the participant suggests is unjustified and unfair, as she was always "good" and therefore undeserving of this outcome.

Linked the sense of injustice and unfairness that some participants described feeling was ideas about who 'deserved' to have a baby and who did not. The idea that other people "got" their baby despite being perceived to be less deserving of it than they were seemed to trigger feelings of anger and frustration for some;

> *You know... you're told when you go to IVF, right don't smoke, you know constant, look at your weight, and all of that. And you're surrounded by people who are pregnant and... you know, going out for a fag, they're overweight, all of it, you know? And you just think: where's, where's the justice in this? - Sally*

It was notable that these sentiments were often expressed in quite a subtle way, perhaps reflecting a lack of socially acceptability of feelings of injustice or anger, as this participant may have felt in reaction to learning a family member was having a baby despite the fact that they had not 'planned' well or wanted a child for as long as the participant had;

> *In the panic of how much we were struggling… they had just gotten married so they got started right away and within 2 months they were pregnant, without having much forethought or planning, and then they were like 'oh my gosh, we're pregnant!' We really weren't expecting that, because before that they had said we haven't really talked about babies much, and we had spoke about babies first when we were dating. - Karen*

3.6.2 What does it mean for my identity and self image not to be a mother?

Participants described that not being able to have children had the significant impact on their self esteem. Interviews indicated that participants often viewed themselves in a negative light (as “a failure”), and that they felt stigmatized and judged as a childless woman. As such, it seemed childlessness posed a threat to both participants’ internal self image as well as how they felt they were perceived by others.

Despite stating that they knew infertility was not their fault, participants indicated that they viewed treatment failure as a personal failure. They described feeling like a disappointment to their partner and their parents for not ‘giving’ them a child or grandchild. They also spoke about feeling like less of a woman for not being able to have children.

> *And there is definitely a feeling of failure, as a woman. Definitely... you never feel, well I will never feel like a complete woman – Mary*

Participants described how the loss of confidence they experienced from treatment failure had a spreading impact on other areas of their life.

> *It was very hard to work. If there was any criticism or stuff, it was like ‘oh that's failing’ – Karen*
>
> *You feel such a big failure for not being able to have a child, sometimes you feel a bit anxious about future failures in anything you do in life - Anna*

Participants descriptions suggested that part of the struggle of moving on from treatment was not just giving up on the dream of becoming a biological mother, but also taking on the social role of a childless woman, and experiencing the stigma that comes along with it. Participants indicated that they were very aware of some of the negative stereotypes associated with being childless, citing qualities like “selfish”, “cold”, “harsh”, and “career focused”, and mentioning stigmatizing terms like “mad cat-lady” and “barren”.

One participant described her frustration about the lack of positive social roles besides motherhood for women, and the sense that childless women ‘can’t win’ as they will inevitably be judged in a negative light;

> *Women are seen I suppose as the life givers really, and if you're not a life giver where do you fit in? Because you're not a man, but if you become this career woman then you must be sleeping with everyone. Or you know...how dare you wear those shoes? Or...you really should make more of an effort. So, I think each way round...and I'm not saying poor me at all because it's just life, but each way you go with this now you're…as a woman I feel very...I feel we're very judged – Jennifer*

Something which came up time and again in interviews was how anxious participants felt when others asked if they have children, as they anticipated being judged in a negative way.

> *You get asked 'have you got children?' and the moment you go 'no' and there's that cold silence… And it's like, um, you know, sometimes you're thinking, hmm, are you just thinking I'm a career woman? – Sally*

> *I just don't want people thinking I'm a hard nosed bitch, because that's the other option. – Sue*

This fear of being judged left many participants feeling like they had to manage their image to others, and many described having a prepared 'line' for how they came to be childless which they would recite to others.

> *I would always follow it up if someone asked 'have you got children?' I would always follow it up with 'well I did want them', because its almost like you get judged because you've chosen to be childless." – Jennifer*

It was interesting to note that the motivation behind having a 'line' like this seemed to be avoiding what participants viewed as an *even more* stigmatized role of a *voluntarily* childless woman. One participant spoke poignantly about being openly stigmatized and judged in this way when an elderly man she met at work asked if she had any children;

> *This gentleman said - 'oh you're not one of these selfish women are you?'. And it was one of those moments where I wish I had said 'no I'm not that lucky'… when he asked have you got children. – Mary*

3.6.3 What does it mean for my social relationships and connections with others not to have children?

Participants spoke about grappling with the social implications of childlessness, and the ways in which not having children influenced their relationships with others. It seemed that not having children, whilst many of their peers did, left many participants feeling marginalized, left out and different from others. Participants also described how others struggled to know how to react to their unsuccessful treatment and childlessness, leaving participants feeling misunderstood and isolated.

Many participants spoke about the challenges of maintaining friendships with friends who had children, often because their lives started to become so different from their own.

> *It's…odd, cause your friends leave you behind in a way. Because they're all doing the same thing. Their children are all of various ages but ultimately their all talking about the same sort of thing - Lisa*

Interviews indicated that not having children challenged participants sense of belonging and place in society, as they felt less included in rituals and events like holidays.

> *You do miss out on loads of things. Especially around holiday things, like Halloween and bonfire night. There's so many things I don't get to do, because I haven't got children* – Sally

> *For a long time it felt like being on the outside looking in – Sue*

Furthermore, not being a part of the mainstream left some participants feeling isolated and different from others.

> *I always felt that I wasn't the same as everybody else (growing up) and that's just gone on […] I would have felt normal had I had children. I would have been one of the other women. - Mary*

> *I just feel almost isolated, a bit different. We're not the norm. – Lucy*

Another way in which childlessness seemed to threaten participants sense of connection to others was the tension it created in relationships with family and friends who *did* have children. Participants spoke about the anxiety surrounding friend and family's pregnancy announcements, baby showers and children's birthdays, as this could evoke difficult feelings of envy and resentment.

> *My friend is pregnant, she's 38 and she sent me pictures of the scan, and I'll be honest, I just ...my initial reaction wasn't very nice. And then it was like 'oh wonderful congratulations!'....but there is always that... (trails off) - Lisa*

> *I've got people at work now that, that are going through IVF treatments and that, and... part of me is kind of thinking I don't want it to work for them. It sounds awful. - Sally*

Participants spoke about how the fact that they were childless made for awkward social interactions even with those closest to them, as other struggled to know how to speak with them about this.

> *People cut off, because they don't know what to say. It's not an illness...and this is a very extreme...it's almost that you've told them that you've got a terminal illness or something. They react - 'oh how do I react? I don't want to say the wrong thing'. So they just don't know what to do. - Mary*

Many participants spoke about their frustration at others around them underestimating the challenges and complexity of coping with unsuccessful treatment, and jumping in to offer solutions to their fertility issues. This left many participants feeling misunderstood, and several stated that they did not feel most of their friends or family could really understand or appreciate what they had been through.

> *People do want to give…offer you advice, and I think we often get the 'why don't you just adopt?' question, because again I think it makes other people feel better – Kate*

> *The thing that annoys me about people with children is they think, "oh, why don't you do that? Or why don't you do this? If you wanted children so much, then you should want to do that." Er, no. It's not that easy. – Sally*

3.7 Resolution: Finding a way to live

Interviews indicated that participants were are different places with respect to grappling with the challenges childlessness raised to their sense of purpose, self image and sense of belonging. Some participants indicated that they were still struggling to find answers to the questions childlessness posed about their identity and their lives, while others spoke about finding some sort of resolution to these questions. Participants who had lived with childlessness for a long time indicated that many of these questions got re-triggered at different stages of their life, suggesting that adjusting to childlessness in not simply a linear process.

The following section, entitled 'Resolution: Finding a way to live' will bring together the factors which appeared to aid participants in the process of moving from feelings of meaninglessness to meaning, from insecurity to self esteem, and from being isolated to having a sense of connection with others. Each of the factors (time, reframing childlessness, taking action, peer support) appear to act as important mediating factors in the adjustment to involuntary childlessness, and will be considered in more detail.

3.7.1 Time

Participants spoke about time as one of the factors which helped heal the grief they experienced after stopping fertility treatments. Many participants described the early period following the end of treatment as an extremely difficult time when their loss felt very raw. However, participants described that the sadness they felt lessened over time.

> *I think it slowly dawns on you, it's not the first thing you think about in the morning, or it's not the main topic of conversations. It slowly slips into..I don't know, this is part of your life, but there are other things to do – Sue*

It seemed that as time went on, infertility and childlessness were no longer the focus of participants lives. ‘Getting on with life’ seemed to help participants realize that they could survive without children, and many reported feeling happy and satisfied with their lives.

> *You don’t see it at the time, you really don’t, but there is life at the end of it. You can have a good… a really good life actually - Sally*
>
> *I can be happy today. Even if I don't have children I can be happy. And that took years to get to - Karen*

Despite reporting that their feelings of loss lessened over time, participants were also keen to highlight that they did not feel they would (or should be expected to) ever ‘get over’ the loss of not being able to have children. Many described that, like with any significant bereavement, the feeling of loss would always persist, although it may get better over time.

> *You still have your moments of grief, for the loss of the whole thing, and you know, the babies, that you know… potentially I could have had - Sally*
>
> *Childlessness isn’t something that just goes away, you know, you learn to live with it. Kind of like a scar that’s always there...and occasionally that gets triggered again - Kate*

Although for most participants’ feelings of grief lessened over time, it seemed clear this was not a linear process, but that certain events or life stages seemed to re-trigger the crisis of childlessness. In the focus group Sue and Molly spoke together about this;

> *I don’t think it ever goes….. But it does get better - Sue*
>
> *Yeah...it’s always there…but there does seem to be times it sort of seems to come back and slaps you in the face – Molly*

Molly, who had finished treatment 25 years previously, described how the pain of childlessness had re-emerged recently as all her friends were suddenly becoming grandparents;

> *We sort of went through a wonderful period when all their kids were grown up and our friends were suddenly back out on the scene and we could go on holiday,*

> *we had a great time then…all our friends seemed to come back to us. And now the last two years it seems every week, 'Guess what? We're going to be a granny or a grandfather'. And I'm actually finding it worse because they're all so doting on their grandchildren in a way that they weren't quite so doting on their own children - Molly*

For her, it seemed having friends become grandparents re-triggered the threat to belonging, leaving her to cope with the feelings of missing out and social exclusion that childlessness posed all over again at this point in her life.

3.7.2 Reframing childlessness

Participants spoke a great deal about how shifting how they thought about childlessness changed how they felt about it. Many described how focusing on the positives, or 'silver linings' of not having children (like having the freedom and flexibility to travel, and having more time to care for aging parents) helped to give them a sense of meaning and positivity about their lives.

> *You create your own reality about it in a way that if you focus on the negative things about it then you will feel that, but if you tap into other aspects of it then you feel differently about it- Jennifer*

> *I just try and compare my life with my friends who maybe do have children. […] they complain that they don't have as much freedom, they don't get lie ins they don't get as many holidays, they don't have as much disposable income. And I try and look at the things that they moan and gripe about in life, and say, well actually I can do this, I can do that because I don't have children. - Lucy*

Participants also spoke about focusing on what they had gained from the experience of living through unsuccessful fertility treatment, often pointing to a sense of being stronger as a person;

> *I've had to grow in that resilience. So I feel like I've grown so much in that my own strength. - Kate*

Several participants also described a strengthening in their relationship with their partner as a result of what they had been through together. It seemed that for some participants, an absence of children created a greater focus on their marriage, and many participants spoke with pride about the ‘family of two’ they had created.

> *We are closer now, it’s brought us closer together. - Patricia*
>
> *You accept the goodness that you've got, you know...and [name of husband] and I are very strongly together, probably stronger now than we were during the whole IVF stuff. - Karen*
>
> *You’ve got to have a really, really good relationship with your partner. Because that, without that... then you would fall apart. And you’ve got to have that support, and it’s got to continue. I think without that, you know, I can see so easily how couples split up. Umm, whereas we’d agreed to, you know, go through this thing together, and we’ve agreed to carry on our lives without children. - Sally*

Several of the participants described that they had been sought out professional help from a therapist, and gave examples of how approaches like Cognitive Behavioral Therapy, mindfulness, Emotional Freedom Technique, and Neurolinguistic programming helped them to think in a different way.

> *With the thai chi, yoga, mindfulness, I started moving on to a more acceptance state of mind. – Karen*
>
> *I did neuro-linguistic programming […] which helped me to look at my negative self talk, and I’m very much more, um… I feel gratitude so much more, you know, very mindful of the little things, and realize now it is the little things that make you happy and not the big things, the physical things. So I’ve shifted my whole mindset around that. – Kate*

Another important aspect of thinking differently about childlessness seemed to involve rejecting the social stigmatizing image of childlessness as a negative thing, and re-envisioning childlessness in a more positive light. For example, two participants spoke positively about not having children as an opportunity to reject gender norms for women;

> *By not having children I feel bit like it's breaking the mold – Lisa*

> *I was in a world where all you did as a woman was having children. […]So...yeah, its like a rejection of was people expect you to be. - Jennifer*

Another participant spoke clearly about locating the 'problem' of childlessness as a problem with society's views, and not a problem within her;

> *Just because society says women should have children doesn't mean they are going to have them. It's not going to happen for everybody. And that should be ok, even if at the moment there is the feeling that it's not ok, it should be ok – Anna*

How able participants felt to re-envision childlessness in this way clearly depended on their personal beliefs about the role of women. For example, one participant spoke about believing her most important role in life should have been as a mother, making missing out on this even more painful for her.

> *Dad and mum obviously wanted me to have children. ....I wouldn't say they weren't proud of my career, but it wasn't what they wanted me to do, my parents just wanted me to have children and that's what I wanted (too). Going through school I rode horses and I thought perhaps I would teach, but I only saw myself as being a wife and mother. So....I know my parents didn't force that on me. That's just the way I feel, and it's quite old fashioned, but that's me - Mary*

3.7.3 Taking action

Several participants spoke about taking action to make changes to their lives after deciding to move on from fertility treatments. For some this entailed more dramatic changes, like changing their job or moving house, whilst others spoke about more subtle changes. What these changes appeared to have in common was a desire to mark the end of one phase of their life, and the start of another. Taking action to build new things in their lives that mattered to them also seemed to help give participants the sense of meaning and purpose that childlessness had put into question.

> *We went off on a big holiday, and when we came back, moved immediately, I changed my job and just sort of....it was almost like, we drew a line under it. You know that was then, and this is our life now. – Molly*

Participants described that whilst undergoing treatment, they structured their lives around the expectation that a baby might come along soon, which had implications for things like career choices and even the type of house they lived in. One participant spoke about selling the house they planned to have children in as an important step in moving on from treatment and pursuing a life without children.

> *It was a four bedroom house, thinking that we were going to grow into it….I'd already planned in my head, which rooms were going to be, you know, the children's rooms, and so that was tough, you know. But again it was...it was holding us back.* – Kate

Another participant described that the grief she was feeling after stopping treatment only started to change nine years after finishing treatment, when she decided to quit her job and pursue training in a different area. She shared that finding something she was passionate about gave her the sense of meaning and self confidence she had felt she was missing since realizing she would not have children.

> *Before the training I was just drifting, I was going to work, doing that and, head down you know. I then I thought, actually there is more to life, that I can have more than this – Patricia*

> *I think it is finding that purpose and meaning. And through (name of organisation) and supporting the people that I do, I kind of feel like maybe....maybe... that's my thing, you know. And no, I don't nurture my own children…but I kind of mother in lots of other ways – Kate*

As the quotations above illustrate, taking action to build alternative sources of meaning in their lives seemed to help participants resolve the questions of purpose which they had previously struggled with.

3.7.4 Peer support

Many participants described that connecting with other childless women played a significant role in helping them to adjust to involuntary childlessness, as it seemed to offer a sense of connection and belonging which participants struggled to feel with others who did have children. They shared that seeing other women living a happy life without children was inspirational, and gave them a sense of hope about the future. This seemed particularly important in the early adjustment period following the end of treatment, when many participants shared that they felt a great deal of fear and despair about what a future without children would be like.

> *You meet people who are in the same boat, who've had similar things happen to them. And that it's okay, you know. I could see it was ok. That it's possible to move on - Karen*

Participants also described the relief they felt in finding other women who could truly understand them, which seemed to resolve some of the isolation they described feeling when friends and family could not appreciate what they had been through.

> *You feel like it's only you. You feel so alone, so it was just a relief to say "me too" – Patricia*
>
> *We would be able the joke about what some silly person in the office said 'Oh have you thought about adoption?'. 'Oh I never thought of that!' and we can laugh about that in way that my sister would never understand. And I think because of that we all helped each other. – Sue*

Another participant shared that the most helpful part of participating in the focus group was reminding herself that she was not alone in what she felt, which seemed to work to resolve some of her feelings of being an outsider and different from others;

> *It's…just I think recognizing that people still feel the same. As I've got older, I've kind of become this freak. The only one without a grandchild or a child, or whatever. So yeah. It helps. - Molly*

Connecting with other childless women also seemed to give participants a sense of not being alone, but rather part of a wider community of women with a shared experience. Participants spoke about women without children as a "sisterhood", and described a sense of empowerment in connecting with other women who do not have children.

Chapter 4: Discussion

"The reality is that you will grieve forever. You will not 'get over' the loss of a loved one; you will learn to live with it. You will heal and you will rebuild yourself around the loss you have suffered. You will be whole again but you will never be the same. Nor should you be the same nor would you want to."

— Elisabeth Kübler-Ross

4.1 Overview

In this final discussion chapter, I start by returning to the research aims set out at the start of this project, and offer a summary of the key findings which work to answer these aims. I will then explore how the findings of this study extend and expand on past research on women's transition from unsuccessful fertility treatment to involuntary childlessness, as well as highlighting areas which this project has appeared to make a novel contribution to the field. I will offer a summary of the key clinical implications of the findings, and reflect on the strengths and limitations of this study. Finally, I will present some recommendations for further research, and offer a concluding summary of this project.

4.2 Summary of findings

Before considering the main finding of this piece of research, let us revisit the central aims set out at the start of this study;

1. *To gain knowledge and deeper insight into how women experience the decision to abandon unsuccessful fertility treatment*
2. *To generate a better understanding of the psychological process that women go through in transitioning from trying to become pregnant to pursuing a life without biological children of their own*

This study generated a model which conceptualizes the journey taken by women from deciding to abandon unsuccessful fertility treatment to transitioning to life with involuntary childlessness. The model depicts three main phases of this journey; ‘living in limbo’ in which women are still undergoing treatment, ‘leaving treatment’ in which women decide to terminate treatment and abandon the search for a resolution to their infertility, and finally ‘learning to live with involuntary childlessness’ in which women start the ‘work’ of grappling with the questions that childlessness seems to raise about the meaning of life, one’s identity and self image, and sense of social belonging.

1. *How women experience the decision to abandon unsuccessful fertility treatment*

With respect to how participants moved through this process on a more detailed level, results indicated that deciding to end fertility treatment was a challenging and an evolving process which unfolded over time. Results did not point to any one factor that triggered the decision to abandon further treatment. Instead, it seems that over time, participants experienced a slow erosion of hope that treatment would work, combined with suffering the mounting ‘costs’ of treatment, including the physical toll, financial costs, and emotion consequences of living through repeated cycles of hope and excitement followed by devastating disappointment. A feeling of one’s life being ‘on hold’ also contributed to the sense from participants that ongoing treatment became an increasingly intolerable position to hold in life. Whatever the particular combination of factors for each participant (ie. increasing debt, a discouraging prognosis from medical professionals), eventually the costs outweighed the hope for success, and the scales tipped in favor of stopping treatment.

Participants described trying to be ‘practical’ and unemotional when deciding to stop treatment, and many were aided by drawing boundaries at certain points, like turning 40 or after three rounds of IVF. In contrast to this cool rational thought process, many reported that the emotional impact of stopping treatment was significant. Although participants described a sense of relief about escaping from the uncertainty and pain of ongoing treatment, it seems ending treatment also meant being hit with the reality of their loss. For those who had a ‘backup plan’ like adoption, this seemed to act as a protective shield from this loss, until they too reached a point where pursuing alternative pathways to parenthood no longer felt feasible.

2. *The psychological process that women go through in transitioning from trying to become pregnant to pursuing a life without biological children of their own*

Results suggested that once the hope for having a child came to an end, the women in this study were faced not only with the task of processing their grief, but also with constructing a different identity, source of purpose, and picture of the future than the one they had expected and longed for. Participants described grappling with questions of what meaning and value their life held if they were not a mother, and with feeling like an outsider in a social context in which motherhood is the norm (and childlessness is stigmatized). Participants seemed to be at different points with respect to resolving the challenges that childlessness posed to them, with some just starting to consider how to live with involuntary childlessness, and others clearly embracing, and even enjoying this alternative pathway. Certain factors, including the passage of time, reframing the meaning of childlessness, taking action to build a new version of the future, and connecting with other childless women all seemed to aid the psychological process of adjusting to involuntary childlessness, and building a meaningful life without children.

4.3 Links to previous research

The theoretical model developed in this study seems to build a bridge between disparate pieces of research identified in the literature review, which together offers a clearer and more robust understanding of the transition from unsuccessful fertility treatment to involuntary childlessness as a whole. Findings from this study add further support to past research suggesting that mounting emotional, physical and financial stressors of ongoing treatment serve as key motivators in the decision to stop treatment (Peddie, Teijlingen & Bhattacharya, 2005; Gameiro et al., 2012). The process of "reaching a limit" in which these stressors no longer feel tolerable is similar to Daniluk's (1996) finding that women reach "*a discrete point when they knew that to move forward and take back their lives*" (p.92). However, unlike Daniluk's suggestion of a clear and obvious point when women "just know" it's time to stop treatment, the findings of this study suggest a more prolonged and subtle build up of stressors and eroding hope over time which eventually tip the scales in favor of stopping treatment. Results from this study indicate that how much time and how much treatment is needed before women reach their "limit" is highly personal, as participants needed to find their own point at which they felt ready to stop treatment, before which contemplating stopping was not considered a possibility. This strengthens Daniluk's conception that the right time to stop is a personal rather than a generic point.

With respect to women's experiences *after* making the decision to stop fertility treatment, the results of this study are largely consistent with Daniluk's (2001) description of "hitting a wall" and Peddie, Teijlingen & Bhattacharya's (2005) finding that ending treatment triggered a "confrontation" with the reality of their infertility. In line with past research (Vogsten, Svanberg & Olsson, 2010; Johansson & Berg, 2005; Lechner, Boleman and Dalen, 2007), the results from this study also suggest that many women will experience intense levels of distress and grief after ending treatment, but that these experiences seem to lessen and improve over time (Daniluk, 2001). However, unlike past studies suggesting a linear process of adjustment and improvement over time (Blenner,1990; Daniluk, 2001), this study offered further credence to the suggestion that adaptation to involuntary childlessness is not just a one off crisis, but may be re-triggered at different stages of the life cycle (like when others are becoming grandparents) (Wirberg et al., 2007). The findings of this study seem to expand and build on Wirberg and colleagues finding that the crisis of childlessness can be 're-triggered' by offering new insight about what type of crises or challenges might be re-triggered at different points in life. For example, results from this study indicated that not becoming a grandparent might re-trigger feelings of being isolated and of not belonging.

The findings of this study strengthen the conclusions made by McCarthy's (2007) that the challenges of childlessness involve not only grief, but what she described as an "existential crisis" of trying to make sense of one's identity and meaning in life without children. The theoretical model developed in this study has focused more on this area of women's experiences, and has gone on to clarify some of the factors which women have described as aiding them in starting to resolve these challenges, like peer support, time, reframing childlessness, and taking action, which appears to be novel in the research literature. The findings from this study indicated that 'moving on' was not a passive process, but involved participants needing to actively grapple with what childlessness meant for their sense of meaning, self image, and social relationships, and that the "work" of resolving these questions often did lead to a sense of resolution. These findings may help to illuminate findings from the quantitative literature that has shown that childless women with a more passive coping style experience higher levels of anxiety, depression and complicated grief after abandoning fertility treatment compared to those with an active coping style (Lechner, Boleman & Dalen, 2007). Furthermore, past research showing significantly higher levels of depression and anxiety amongst women still hoping for pregnancy (either by actively pursuing treatment or “passively” hoping for a child) compared to women who had moved forward toward other life goals following failed treatment (Verhaak et al., 2007b) makes sense in the context of the model produced in this study. Women still hoping for pregnancy may be conceived as being “stuck” in *Living in limbo,* which participants in this study described as an increasingly intolerable way to live, which did not seem to resolve until they started the “work” of *Learning to live with involuntary childlessness*.

With respect to past research indicating that living through unsuccessful treatment may generate feelings of personal growth and gain (Su & Chen, 2006; Daniluk, 2001), participants in this study did talk about gains, particularly in relation to a strengthening of their relationship, and feeling stronger as a person for having ‘survived’ infertility. Results from this study indicated that participants could identify both losses and gains from going through unsuccessful fertility treatment.

Something which was identified much more strongly in this study compared to past research was how the stigma of childlessness seemed to influence participants’ experiences of unsuccessful fertility and involuntary childlessness. For example, participants described their awareness of derogatory terms for childless women (“barren”, “crazy cat lady”) and expressed their anxiety about being misjudged as a “career woman”. Apart from some references to experiences of marginalization (Daniluk, 1996), and feelings of inferiority to other women with children (Wirberg et al., 2007) consideration of the social context of childlessness appears to be largely absent from past research literature on adjustment to involuntary childlessness. Although I can only speculate about why this may be, one factor may be the general tendency of medical and psychological research (particularly research from a more positivist framework) to seek out and conceptualize problems as ‘symptoms’ residing within individuals, rather than considering the social construction of such ‘problems’ within a specific cultural and historical context.

4.4 Links to theory

In the introductory chapter of this dissertation Schlossberg's (1981) Model of Transitions was presented as a framework for understanding how people adapt to transitions in life. As discussed, Schlossberg's model suggests that several variables are at play which influence adaptation, which include not only individual characteristics of the person experiencing the transition, but also characteristics of the pre and post transition environments, and characteristics of the particular transition. Unlike past research which has focused a great deal on the individual characteristics of women coping with treatment failure and involuntary childlessness (like personality factors and coping style), the results of this study suggest that the post transition environment and the particular characteristics of transitioning to childlessness within the context of fertility treatment are important factors to consider. A novel finding of this research highlights the challenging nature of the post transition environment for childless women, in which women can feel socially marginalized and judged.

Furthermore, the results of this study offer further insight into why transitioning to childlessness following failed fertility treatment in particular may post unique challenges compared to other life transitions. Participants' accounts suggested that whilst women were still in treatment, their life was on hold, and they were 'living in limbo' – not yet sure whether their future would be as a mother or not. Therefore, although women were living with involuntary childlessness even then, it seemed they were not *adapting* to the reality of childlessness, or as Schlossberg defined it, they were not "integrating the transition into his or her life" (p. 7). Instead, results suggested that this process of adaptation and change only really began once treatment had been abandoned, at which time participants began the work of 'learning to live with involuntary childlessness'. With this framework in mind, it is perhaps unsurprising that past evidence has suggested that those who persist with ongoing fertility treatment in the long term struggle more than those who have 'moved on' (Verhaak et al., 2007b), as those undergoing treatment may be aware of some of the questions or threats that childlessness might pose - like the questions of meaning, self-image and belonging described in this study - but will unlikely be at the stage were they are working to adapt to and resolve these challenges.

Another theory which seems to offer some insight into the unique challenges of adjusting to involuntary childlessness is the concept of ‘disenfranchised grief’. This study found that moving on from unsuccessful fertility treatment often triggered deep feelings of loss and grief. However, unlike what normally occurs with the death of a loved one, when the hope for a long wished for baby dies, there is no funeral, condolences, or time off of work. Participants in this study described that the loss they were experiencing was invisible to most people around them, and that they themselves often did not recognize until much later that they might be grieving. This seems closely akin to Doka’s (1989) concept of “disenfranchised grief” defined as "grief that is experienced when a loss cannot be openly acknowledged, socially sanctioned, or publicly mourned" (p. 4). Disenfranchised grief has commonly been linked with losses from suicide, abortion, miscarriage or drug overdoses. This study lends support to it’s relevance for the ambiguous and invisible losses associated with infertility and childlessness. This type of loss is seen as increasing distress and complicating the grieving process as grievers are more likely to suffer in isolation, lack social support and validation for their loss, and be excluded from many of the cultural rituals used to aid the processing of loss.

Finally, ideas from trauma theory may help to further conceptualize the emotional and psychological impact of infertility and childlessness described in this study. The *theory of shattered assumptions* proposes that traumatic events threatened people’s ‘taken for granted’ assumptions about themselves and the world, like that the world is a good and fair place, that things happen for a reason, and that the person themselves are invulnerable to harm and in control (Janoff-Bulman, 1992). Within this framework recovery from trauma involves rebuilding one’s assumptions and constructing a new worldview which incorporates the traumatic experiences. This model seems to speak to the threat or ‘shattering’ that women in this study described to their assumptions about their meaning and purpose in the world, as well as the work they did to re-conceptualize their lives and their identity in a more positive way.

4.5 Clinical implications

Findings from this study and from past research have suggested that while undergoing fertility treatment, women often maintain high levels of hope and optimism that treatment will be successful. Whilst this may be adaptive in the sense of carrying women through the stress of treatment, it also seems to leave many feeling ill-prepared and unsure of what to expect when treatment fails. Therefore, information about what the process of psychological adjustment following the end of fertility treatment might look like, and the factors which helped other women with similar experiences might be useful. Some ideas of how to achieve this could be encouraging fertility clinics to raise the profile of possible treatment failure by having information about this (like leaflets and online resources) accessible to patients, by including this explicitly in consultations about treatment options, and by ensuring that all clinics have clear, accurate and easy to understand statistics about the likelihood of successful fertility treatment. Findings from this study could help inform the material used in these recourses, highlighting some of the common experiences women might face at this time (including grief, and challenges to self esteem, feelings of purpose and meaning, and connections to others). Such resources could also signpost patients to organizations offering peer support for those coping with involuntary childlessness, as well as information about access to professional therapeutic help.

With respect to gaining support from a counsellor or therapist, results from this study echo past research that fertility patients would likely benefit from some professional support during the decision making process of when to leave treatment, as patients will likely be grappling with the difficult task of weighing up the pros and cons of further treatment. Therapeutic support together as a couple at this time would also likely be helpful in creating a space in which couples can communicate with one another about issues like when to terminate treatment and whether or not pursue fostering or adoption, as results from this study indicated that disagreement in this area could lead to an extra source of stress.

In addition to this, results highlight that access to support should be made available longer term for those who have abandoned unsuccessful treatment. National recognition of the psychological stress of fertility treatment has meant that all UK fertility clinics are required to offer some sort of counselling to patients (HFEA, 1990), and NICE guidelines state that “counselling should be offered before, during and after investigation and treatment, irrespective of the outcome of these procedures” (NICE, 2013). However in practice, counselling has continued to focus on those still in treatment, and contact with counsellors often end when treatment ends (Monach, 2013). Therefore, it may be that better monitoring and tighter regulation of fertility clinics are needed to ensure long term counselling support is readily accessible.

This study offers further support to a growing body of evidence (Daniluk 1996, 2001; Verhaak et al., 2007a) that the most psychologically trying period of fertility treatment may be not whilst undergoing treatment, but after abandoning unsuccessful treatment. Results also suggest that women may go through a period of grieving, ‘hibernation’, and just ‘wanting to be’ following the end of treatment, and that it may take some time before they turn towards the future to consider some of the implications of childlessness on their lives. Although this may be a particularly helpful time to seek support from a therapist or counsellor to explore these challenges, for most women this will be at a time when they no longer have any contact with their fertility clinic, and the social expectation may be that they should ‘be over’ their loss by then. Therefore, it may be that when women reach a point where they are most in need of professional support, they are at the stage of their journey with infertility when they have least access to it. As such, a key clinical implication of this study is that access to professional support should be extended, ensuring that women are able to return to counsellors at fertility clinics even after they have terminated treatment, and that information is provided which signposts women to local NHS sponsored and private psychological support services. Furthermore, awareness of the psychological impact of unresolved infertility should be raised in adult mental health services and primary care services, as a lack of understanding and acknowledgement of infertility and childlessness as a significant loss may mean these issues are easily overlooked as an important factor amongst women presenting for support from mental health services.

The findings of this study point to certain types of help and support that might be particularly helpful in resolving some of the challenges that involuntary childlessness seems to pose to women. For example, results from this study highlighted that peer support from other childless women was especially helpful, as it seemed to aid women in feeling less alone, more understood, and helped to resolve the threat to belonging which childlessness posed in their lives. Results also highlighted that participants were aided by shifting their mindset and perspectives on childlessness, suggesting the possible benefits of cognitive approaches which work to identify and change unhelpful beliefs or thinking patterns (like Cognitive Behavioral Therapy or Mindfulness based approaches). Talking therapy as well as peer support may also help provide women with a non-judgmental space to talk some of the more “taboo” or difficult emotional that could come along with infertility and childlessness, like feelings of anger about the injustice of infertility, and envy towards others who have children.

Based on the finding that women felt helped by ‘taking action’ to build alternative sources of meaning and purpose, therapeutic approaches which help women to identify new life goals might also be particularly helpful. One such approach is Acceptance and Commitment Therapy (ACT) (Hayes, Luoma, Bond, Masuda & Lillis, 2006), which in addition to its focus on promoting a more mindful relationship with distressing thoughts, emphases ‘value-based living’. Helping those facing involuntarily childlessness to consider and clarify the core values in their life may be helpful in several ways. Firstly, it may help them to consider *other* life domains separate from having children which hold meaning for them (and which may have been lost or obscured through the all consuming focus on fertility treatment). Secondly, ACT approaches may be helpful in clarifying the underlying values motivating the desire for children (like nurturing someone else, building a legacy, or having the opportunity to feel needed) in order to help women and couples to consider alternative routes to building a fulfilling life which are in line with their values.

Although there is no reason to think that the clinical implications made in this study (like therapeutic help with reframing childlessness, taking action to identify different sources of meaning and purpose, and peer support) may not also be relevant to men, further research is needed to explore how men experience moving on from unsuccessful fertility treatment in order to inform how men can be best supported through this process.

Finally, the results of this study highlighted how social factors (like stigma, social marginalization, and the lack of social recognition for their loss) seem to contribute to the challenges women face in coming to terms with unsuccessful treatment and involuntary childlessness. Participants in this study described how fears of being judged (as well as overt experiences of being stigmatized as a ‘selfish’ woman), feeling left out and ostracized from their peers and community, and the invisibility of their grief and loss added an extra layer of suffering to the loss of infertility and childlessness. Therefore, when considering what might help women in this situation, it seems important to go beyond clinical implications at individual level to considering ways of challenging some the discriminatory and stigmatizing social discourses around infertile or childless women. Initiatives already exist which seem to be working towards these aims, including the National Fertility Awareness Week and

‘Hidden faces’ campaign, which both work to raise awareness about infertility, dispel myths, and increase understanding of those who suffer with infertility and involuntary childlessness (see Appendix Q campaign leaflet). Encouraging healthcare professionals and women experiencing permanent infertility to get involved in such initiatives may help to start to change the social narratives which contribute to the stigma of infertility and childlessness in our culture today.

4.6 Methodological reflections

4.6.1 Strengths

One of the main strengths of this study is that it was innovative, and attempted to shed light on a process of adjustment that has previously been poorly understood. Whilst a small body of past research has offered some insight into women’s lived experience of unsuccessful fertility treatment, this study was novel in its aim to produce an explanatory model for understanding the process of adjustment from pursuing treatment to coming to terms with involuntary childlessness. The model developed in this study aims to offer a practical and useful framework for healthcare professionals and for those coping with unsuccessful fertility treatment to anticipate what some of the challenges of adjusting to unsuccessful fertility treatment might be, as well as the factors which have aided those who have been through it. Therefore, a strength of this study is its ability not only to extend knowledge but also the potential improve practice, making a more significant contribution to the field.

Although it must be acknowledged that the findings of this study are a co-construction between myself and the participants, it is strength of this study that several measures were taken to ensure that the interpretation and claims made in this study were generated from (and not imposed on) participants’ experiences. For example, going in with a more ‘naïve’ stance with respect to previous theory and research, tracking my developing analysis through memos, and asking for feedback from participants about the developing theory helped to ensure that the model developed in this study was in fact ‘grounded’ in participant experiences, increasing the credibility of findings. Furthermore, the use of both interviews and a focus group allowed for an exploration of the phenomenon of moving on from unsuccessful fertility treatment through different lenses and vantage points, adding to a richer and more in depth understanding of participant experiences.

Finally, although the sample lacked diversity in some areas, the sample did include women from a range of time points since stopping fertility treatment, including women who had completed treatment just 3 months earlier all the way to 25 years previously. This broad range of experiences helped to offer insight about how women's experiences of unsuccessful treatment and involuntary childlessness change over time.

4.6.2 Limitations

A limitation of this study is that participants were mainly recruited through support websites for women living with involuntary childlessness. It is possible that women who seek support from charities like these following unsuccessful fertility treatment, and those who access this support many years after ending treatment, differ from those who do not. For example, it may be that those who have come to terms with their infertility and childlessness would be less likely to seek support and therefore would not be part of this study. Further research which employs a random sampling approach (perhaps by following up with women who had accessed NHS or private fertility treatment) would help clarify if women who choose to seek out peer support are representative of the broader population of women who have experienced unsuccessful fertility treatment.

Certain groups like non-English speakers and women without access to the internet were also likely excluded from participation in this study, which should be taken into consideration in future research.

Although the sample used in this study was diverse with respect to age, time since last treatment, and geographic location (with participants from England, Ireland and Scotland), it lacked diversity in other areas. With only heterosexual, White-British and Asian-British women coming forward to participate, the model may be limited in offering insight into the experience of women in same sex relationships and women from other cultural backgrounds.

Due to time scale and scope of this project, this study employed a cross sectional design, and participants were only interviewed on a single occasion. This could be viewed as a limitation, as participants were asked to recall and reflect on experiences that (for some) had occurred many years previously. It is possible that a longitudinal approach in which women were interviewed at different point along their journey during and after unsuccessful fertility treatment could allow for deeper insight into how women's experience changes over time.

4.7 Suggestions for further research

Conducting this study with a larger and more diverse sample of women would likely extend and expand the understandings of adjustment to unsuccessful fertility treatment developed in this study. As the participants in this study included only women from a White-British and Asian-British backgrounds, it would be beneficial to explore whether the model developed in this study is reflective of the experiences of women from other cultural backgrounds, as well as for women from different socioeconomic backgrounds, and those in same-sex relationships.

None of the women in this study had adopted a child, either because they or their partner did not want to, or because they tried but were not successful in the adoption process. As statistics show only a minority of couples (11% to 21%) will go on to successfully adopt a child after leaving treatment (Sydsjö, Svanberg, Lampic & Jablonowska, 2011; Walschaerts et al., 2013; Troude et al., 2016), the sample recruited for this study do represent the norm with respect to adoption. However, it would be interesting to know how adopting a child influences women's experiences of moving on from unsuccessful fertility treatment, which further research with this population might illuminate.

Whilst all the women in this study described that they had no plans to return to fertility treatment, and none had adopted, this is not to say that these factors will not change in the future. For example, it is possible that some could return to treatment, some may end up choosing to adopt, and some may even become pregnant. A similar study employing a longitudinal design would have the ability to track such experiences and consider how these alternative pathways influence women's experiences. Furthermore, a longitudinal design could offer a deeper insight into women's experiences 'in the moment', as this study relied on women's recollections of experiences (like deciding to abandon fertility treatment) which for some had occurred many years previously. Interviewing women several times at different points along their journey of moving from unsuccessful fertility treatment could offer a deeper and more rich exploration of some of the phases of transition identified in this study.

Finally, this study focused on the perspective of women and did not include the views of male partners. This may be seen as an advantage of this study as it helped to shed light on some of the gender based factors (like the stigma of being a childless woman) that seemed to have an important impact on how women experienced unsuccessful fertility treatment, and which has not been identified in much of the previous research literature which used mainly data gathered from couple interviews. However, a draw-back of this specific focus was that the relational context in which the women experienced childlessness was less explored and elaborated than would have been possible had couples been interviewed. In addition, it must be acknowledged that more research needs to be done to understand the experiences of men coping with infertility and involuntary childlessness, as this is an area that has been neglected in the infertility research literature. Therefore, conducting a similar study exploring men's experiences of moving on from unsuccessful fertility treatment could offer insight into the ways in which men and women experience this process in similar or different ways.

4.8 Conclusions

This study aimed to explore the experiences of women for whom fertility treatment was not successful in helping them to have a baby. Using Grounded Theory, an explanatory model was developed showing the process of adjustment from pursuing treatment to coming to terms with involuntary childlessness. Results suggested that the decision to abandon fertility treatment gave participants a sense of relief for being able to move beyond the physical, financial and emotional stressors of treatment, but also brought them face to face with the reality that their hopes for a baby had come to an end. Results also suggested that after making this decision, participants were faced not only with the challenges of grieving this loss, but with re-evaluating and re-establishing a new sense of purpose, meaning, identity and self worth as a childless woman. This study aims to make a novel and valuable contribution to the field by offering a model with practical applications, both to help women anticipate the process of adjustment over time, as well as highlighting factors which seem to help women through this process.

The findings of this study suggest that the emotional challenges of coping with unsuccessful treatment extend well beyond the end of treatment, highlighting the need for good access to therapeutic support for women coping with involuntary childlessness longer term. Results also point to certain sources and types of support which may be particularly helpful, including peer support from other childless women, and therapeutic interventions which help women to develop more positive perspectives on childlessness and to identify alternative sources of fulfillment. The results of this study also point to the need for activities which work to challenge the misconceptions and stigma surrounding infertility and childlessness which add an extra layer of suffering to these experiences. Further research is needed to understand how these finding might extend to other groups, including those from different cultural backgrounds, men, and those in same-sex relationships.

References

Andrews, F. M., Abbey, A., & Halman, L. J. (1992). Is fertility-problem stress different? The dynamics of stress in fertile and infertile couples. *Fertility and Sterility*, *57*(6), 1247-1253.

Bailey, A., Ellis-Caird, H., & Croft, C. (2017). Living through unsuccessful conception attempts: a grounded theory of resilience among women undergoing fertility treatment. *Journal of Reproductive and Infant Psychology*, 1-10.

Barbour, R.S. & Kitzinger, J. (Eds.) (1999) Developing focus group research. London: Sage.

Benazon, N., Wright, J., & Sabourin S. (1992). Stress, sexual satisfaction, and marital adjustment in infertile couples. *Journal of Sex and Marital Therapy, 18*, 273 - 284.

Berrington, A. (2015). *Childlessness in the UK*. (Working paper No. 69), Southhampton: Centre for Population Change.

Bergart, A. M. (2000). The experience of women in unsuccessful infertility treatment: what do patients need when medical intervention fails? *Social Work in Health Care*, *30*(4), 45-69.

Bhattacharya, S., Johnson, N., Tijani, H. A., Hart, R., Pandey, S., & Gibreel, A. F. (2010). Female infertility. *BMJ Clinical Evidence*, *11*, p. 0819.

Blenner, J. L. (1990). Passage through infertility treatment: a stage theory. *Journal of Nursing Scholarship*, *22*(3), 153-158.

Boden, J., & Boden, J. (2007). When IVF treatment fails. *Human Fertility*, *10*(2), 93-98.

The British Psychological Society. (2014). *Code of Human Research Ethics*. Retrieved from http://www.ed.ac.uk/files/atoms/files/bps_code_of_human_research_ethics.pdf

Burr, V.(2003). *Social Constructionism*. (2nd Ed), London: Routledge.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. London, UK: SAGE.

Chen, T. H., Chang, S. P., Tsai, C. F., & Juang, K. D. (2004). Prevalence of depressive and anxiety disorders in an assisted reproductive technique clinic. *Human Reproduction, 19*(10), 2313-2318.

Cousineau, T. M., & Domar, A. D. (2007). Psychological impact of infertility. Best Practice & Research. *Clinical Obstetrics & Gynaecology, 21*, 293–308.

Covington, S. N., & Burns, L. H. (Eds.). (2006). *Infertility counseling: A comprehensive handbook for clinicians*. Cambridge University Press.

Critical Appraisal Skills Programme (2017). *CASP Qualitative Checklist*. [online] Retrieved from: http://www.casp-uk.net/checklists

Daniluk, J. C. (1996). When treatment fails: The transition to biological childlessness for infertile women. *Women & Therapy, 19*(2), 81-98.

Daniluk, J. C. (2001). Reconstructing their lives: a longitudinal, qualitative analysis of the transition to biological childlessness for infertile couples. *Journal of Counseling and Development: JCD, 79*(4), 439.

Dey, I. (1993). *Qualitative Data Analysis*. London. In Strauss, A. & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory.* 2nd ed. SAGE Publications, Thousand Oaks: California.

Doka, K., (1989). *Disenfranchised grief: Recognizing hidden sorrow*. Lexington, MA: Lexington Books.

Domar, A. D., Zuttermeister, P. C., & Friedman, R. (1993). The psychological impact of infertility: a comparison with patients with other medical conditions. *Journal of Psychosomatic Obstetrics and Gynecology*, *14*, 45-45.

Dyer, S. J., Abrahams, N., Hoffman, M., & van der Spuy, Z. M. (2002). Infertility in South Africa: women's reproductive health knowledge and treatment-seeking behaviour for involuntary childlessness. *Human Reproduction*, *17*(6), 1657-1662.

Ellingson, L. L. (2009). *Engaging crystallization in qualitative research: An introduction*. Sage.

Eugster, A., & Vingerhoets, A. J. J. M. (1999). Psychological aspects of in vitro fertilization: a review. *Social Science & Medicine*, *48*(5), 575-589.

Folkman, S., & Lazarus, R. S. (1988). The relationship between coping and emotion: Implications for theory and research. *Social Science & Medicine*, *26*(3), 309-317.

Gameiro, S., Boivin, J., Peronace, L., & Verhaak, C. M. (2012). Why do patients discontinue fertility treatment? A systematic review of reasons and predictors of discontinuation in fertility treatment. *Human Reproduction Update*, *18*(6), 652-669.

Glaser, B. G. (1978). *Theoretical sensitivity: Advances in the methodology of grounded theory*. Sociology Pr.

Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory*. Weidenfield & Nicolson, London.

Greil, A. L. (1991). A secret stigma: The analogy between infertility and chronic illness and disability. *Advances in Medical Sociology*, *2*(1), 17-38.

Greil, A. L. (1997). Infertility and psychological distress: a critical review of the literature. *Social Science & Medicine*, *45*(11), 1679-1704.

Greil, A. L., Slauson-Blevins, K., & McQuillan, J. (2010). The experience of infertility: a review of recent literature. *Sociology of Health & Illness*, *32*(1), 140-162.

Hammarberg, K., Astbury, J., & Baker, H. W. G. (2001). Women's experience of IVF: a follow-up study. *Human Reproduction*, *16*(2), 374-383.

Hayes, S. C., Luoma, J. B., Bond, F. W., Masuda, A., & Lillis, J. (2006). Acceptance and Commitment Therapy: Model, processes and outcomes. *Behaviour Research and Therapy*, *44*, 1–25.

Human Fertilisation and Embryology Act. (1990). Chapter 37, HMSO, London. Retrieved from http://www.legislation.gov.uk/ukpga/1990/37/pdfs/ukpga_19900037_en.pdf

Human Fertilisation and Embryology Authority. (2014). *Fertility treatment in 2013 trends and figures*. Retrieved from http://www.hfea.gov.uk/docs/HFEA_Fertility_Trends_and_Figures_2013.pdf

Human Fertilisation and Embryology Authority. (2007). *A long term analysis of the HFEA Register data 1991-2006. 2007*. Retrieved from http://www. hfea. gov. uk/docs/Latest_long _term_data_analysis_report_91-06. pdf.

Hynes, G. J., Callan, V. J., Terry, D. J., & Gallois, C. (1992). The psychological well-being of infertile women after a failed IVF attempt: The effects of coping. *Psychology and Psychotherapy: Theory, Research and Practice*, *65*(3), 269-278.

Inhorn, M., & Van Balen, F. (2002). *Infertility around the globe: New thinking on childlessness, gender, and reproductive technologies*. University of California Press.

Janoff-Bulman. R. (1992). *Shattered assumptions: Towards a new psychology of trauma*. New York: Free Press.

Johansson, M., & Berg, M. (2005). Women's experiences of childlessness 2 years after the end of in vitro fertilization treatment. *Scandinavian Journal of Caring Sciences*, *19*(1), 58-63.

Jordan, C., & Revenson, T. A. (1999). Gender differences in coping with infertility: a meta-analysis. *Journal of Behavioral Medicine*, *22*(4), 341-358.

Kübler-Ross, E., Kessler, D., & Shriver, M. (2014). *On grief and grieving: Finding the meaning of grief through the five stages of loss*. Simon and Schuster.

Lechner, L., Bolman, C., & Van Dalen, A. (2007). Definite involuntary childlessness: associations between coping, social support and psychological distress. *Human Reproduction*, *22*(1), 288-294.

Lee, G. L., Hui Choi, W. H., Chan, C. H., Chan, C. L., & Ng, E. H. (2009). Life after unsuccessful IVF treatment in an assisted reproduction unit: a qualitative analysis of gains through loss among Chinese persons in Hong Kong. *Human Reproduction*, *24*(8), 1920-1929.

Leiblum, S. R., Aviv, A., & Hamer, R. (1998). Life after infertility treatment: a long-term investigation of marital and sexual function. *Human Reproduction*, *13*(12), 3569-3574.

Leiblum, S. R., Kemmann, E., Colburn, D., Pasquale, S., & DeLisi, A. M. (1987). Unsuccessful in vitro fertilization: a follow-up study. *Journal of Assisted Reproduction and Genetics*, *4*(1), 46-50.

Litt, M. D., Tennen, H., Affleck, G., & Klock, S. (1992). Coping and Cognitive factors in adaptation toin vitro fertilization failure. *Journal of Behavioral Medicine*, *15*(2), 171-187.

Lok, I. H., Lee, D. T. S., Cheung, L. P., Chung, W. S., Lo, W. K., & Haines, C. J. (2002). Psychiatric morbidity amongst infertile Chinese women undergoing treatment with assisted reproductive technology and the impact of treatment failure. *Gynecologic and Obstetric Investigation*, *53*(4), 195-199.

McCarthy, M. P. (2008). Women's lived experience of infertility after unsuccessful medical intervention. *Journal of Midwifery & Women's Health*, *53*(4), 319-324.

Maconochie, N., Doyle, P., & Prior, S. (2004). The National Women's Health Study: assembly and description of a population-based reproductive cohort. *BMC Public Health*, *4*(1), 35.

Monach, J. (2013). Developments in infertility counselling and its accreditation. *Human Fertility*, *16*(1), 68-72.

National Institute for Health and Care Excellence. (2013) *Fertility: assessment and treatment for people with fertility problems* (NICE, London) CG156, Retrieved from http://www.nice.org.uk/CG156.

Newton, C. R., Hearn, M. T., & Yuzpe, A. A. (1990). Psychological assessment and follow-up after in vitro fertilization: assessing the impact of failure. *Fertility and Sterility*, *54*(5), 879-886.

Oddens, B. J., den Tonkelaar, I., & Nieuwenhuyse, H. (1999). Psychosocial experiences in women facing fertility problems—a comparative survey. *Human Reproduction*, *14*(1), 255-261.

Pasch, L. A., Dunkel-Schetter, C., & Christensen, A. (2002). Differences between husbands' and wives' approach to infertility affect marital communication and adjustment. *Fertility and Sterility*, *77*(6), 1241-1247.

Peddie, V. L., Van Teijlingen, E., & Bhattacharya, S. (2005). A qualitative study of women's decision making at the end of IVF treatment. *Human Reproduction*, *20*(7), 1944-1951.

Rockliff, H. E., Lightman, S. L., Rhidian, E., Buchanan, H., Gordon, U., & Vedhara, K. (2014). A systematic review of psychosocial factors associated with emotional adjustment in in vitro fertilization patients. *Human Reproduction Update*, *20*(4), 594-613.

Schlossberg, N. K. (1981). A model for analyzing human adaptation to transition. *The Counseling Psychologist*, *9*(2), 2-18.

Schmidt, L., Holstein, B., Christensen, U., & Boivin, J. (2005). Does infertility cause marital benefit?: An epidemiological study of 2250 women and men in fertility treatment. *Patient education and counseling*, *59*(3), 244-251.

Shontz, F. C. (1975). *The psychological aspects of physical illness and disability*. MacMillan Publishing Company.

Silverman, D. (2013). *Doing qualitative research: A practical handbook*. SAGE Publications Limited.

Su, T. J., & Chen, Y. C. (2006). Transforming Hope: The Lived Experience of Infertile Women Who Terminated Treatment After inVitro Fertilization Failure. *Journal of Nursing Research*, *14*(1), 46-54.

Sydsjö, G., Ekholm, K., Wadsby, M., Kjellberg, S., & Sydsjö, A. (2005). Relationships in couples after failed IVF treatment: a prospective follow-up study. *Human reproduction*, *20*(7), 1952-1957.

Sydsjö, G., Svanberg, A. S., Lampic, C., & Jablonowska, B. (2011). Relationships in IVF couples 20 years after treatment. *Human reproduction*, *26*(7), 1836-1842.

Sydsjö G, Wadsby M, Kjellberg S and Sydsjö A (2002) Relationship and parenthood in couples after assisted reproduction and in spontaneous primiparous couples: a prospective long-term follow-up study. *Hum Reproduction* 17, 3241–3250.

Terry, D. J., & Hynes, G. J. (1998). Adjustment to a low-control situation: Reexamining the role of coping responses. *Journal of Personality and SocialPpsychology*, *74*(4), 1078.

Tracy, S. J. (2010). Qualitative quality: Eight "big-tent" criteria for excellent qualitative research. *Qualitative Inquiry, 16*(10), 837-851.

Troude, P., Santin, G., Guibert, J., Bouyer, J., de La Rochebrochard, E., & DAIFI Group. (2016). Seven out of 10 couples treated by IVF achieve parenthood following either treatment, natural conception or adoption. *Reproductive biomedicine online*, *33*(5), 560-567.

UK Government (1998). *Data Protection Act.* London, UK: HMSO.

Unruh, A. M., & McGrath, P. J. (1985). The psychology of female infertility: toward a new perspective. *Health Care for Women International*, *6*(5-6), 369-381.

Urquhart, C. (2013*). Grounded theory for qualitative research: A practical guide*. London, UK: SAGE.

Verhaak, C. M., Smeenk, J. M. J., Evers, A. W. M., Kremer, J. A. M., Kraaimaat, F. W., & Braat, D. D. M. (2007a). Women's emotional adjustment to IVF: a systematic review of 25 years of research. *Human Reproduction Update*, *13*(1), 27-36.

Verhaak, C. M., Smeenk, J. M. J., Nahuis, M. J., Kremer, J. A. M., & Braat, D. D. M. (2007b). Long-term psychological adjustment to IVF/ICSI treatment in women. *Human Reproduction*, *22*(1), 305-308.

Verhaak, C. M., Smeenk, J. M. J., Van Minnen, A., Kremer, J. A. M., & Kraaimaat, F. W. (2005). A longitudinal, prospective study on emotional adjustment before, during and after consecutive fertility treatment cycles. *Human Reproduction*, *20*(8), 2253-2260.

Volgsten, H., Svanberg, A. S., & Olsson, P. (2010). Unresolved grief in women and men in Sweden three years after undergoing unsuccessful in vitro fertilization treatment. *Acta Obstetricia et Gynecologica Scandinavica*, *89*(10), 1290-1297.

Walschaerts, M., Bujan, L., Parinaud, J., Mieusset, R., & Thonneau, P. (2013). Treatment discontinuation in couples consulting for male infertility after failing to conceive. *Fertility and sterility, 99*(5), 1319-1323.

Weaver, S. M., Clifford, E., Hay, D. M., & Robinson, J. (1997). Psychosocial adjustment to unsuccessful IVF and GIFT treatment. *Patient Education and Counseling, 31*(1), 7-18.

Webb, R.E. and Daniluk, J.C. (1999) The end of the line: infertile men's experiences of being unable to produce a child, *Men & Masculinities, 2*(1) 6–25.

Whiteford, L. M., & Gonzalez, L. (1995). Stigma: the hidden burden of infertility. *Social Science & Medicine*, *40*(1), 27-36.

Wilkinson, S. (1998) Focus groups in feminist research power, interaction, and the co-construction of meaning. *Women's Studies International Forum 21*,111–125.

William M. Mercer Company (1997). *Women's Health Issues: Infertility as a Covered Benefit.*

Williams, K. E., Marsh, W. K., & Rasgon, N. L. (2007). Mood disorders and fertility in women: a critical review of the literature and implications for future research. *Human Reproduction Update*, *13*(6), 607-616.

Wirtberg, I., Möller, A., Hogström, L., Tronstad, S. E., & Lalos, A. (2007). Life 20 years after unsuccessful infertility treatment. *Human Reproduction, 22*(2), 598-604.

Worden, J. W. (2008). *Grief counseling and grief therapy: A handbook for the mental health practitioner*. Springer Publishing Company.

Wright, J., Duchesne, C., Sabourin, S., Bissonnette, F., Benoit, J., & Girard, Y. (1991). Psychosocial distress and infertility: men and women respond differently. *Fertility and Sterility, 55*(1), 100-108.

Yardley, L. (2014). Demonstrating validity in qualitative psychology. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp. 235-251). London: Sage.

Zegers-Hochschild, F., Mansour, R., Ishihara, O., Adamson, G. D., de Mouzon, J., Nygren, K. G., & Sullivan, E. A. (2014). International Committee for Monitoring Assisted Reproductive Technology: world report on assisted reproductive technology, 2005. *Fertility and Sterility*, *101*(2), 366-378.

Appendix A - CASP Quality Appraisal

	Clear statement of aims?	Qualitative method appropriate?	Design appropriate to address aims, justified design/method?	Recruitment strategy appropriate?	Data collected appropriately?	Evidence of self-reflexivity of researcher?	Ethical issues considered?	Data analysis sufficiently rigorous?	Clear statement of findings, credibility addressed?	How valuable is research?
Bergart, 2000	No (Vague, broad)	Yes	Can't tell (No justification for design)	Can't tell (Too little info to judge)	Can't tell (Too little info to judge)	No	No (No explicit info provided)	Can't tell (Too little info to judge)	No (Credibility not addressed)	Limited due to lack of info on credibility
Blenner, 1990	Yes	Yes	Can't tell (No justification for design)	Can't tell (Too little info to judge)	Can't tell (Too little info to judge)	No	No (No explicit info provided)	Can't tell (Too little info to judge)	Yes	Limited discussion of clinical implications
Boden, 2007	Yes	Yes	Yes	Can't tell (Too little info to judge)	Can't tell (Too little info to judge)	No	Yes	No(insufficient data shown to support claims)	No	Limited value in understanding experience of childlessness due to sample
Daniluk, 1996	Yes	Yes	Yes	Yes	Can't tell (Too little info to judge)	Yes	No (No explicit info provided)	Yes	Yes	Valuable contribution, clear clinical implications
Daniluk, 2001	Yes	Yes	Yes	Yes	Yes	No	No(No explicit info provided)	Yes	Yes	Valuable contribution, clear clinical implications
Johansson & Berg, 2005	Yes	Yes	Yes	Can't tell (Too little info to judge)	No (some data analyzed 7yrs after collection)	No	Can't tell (Too little info to judge)	Can't tell (Too little info to judge)	No (Credibility not addressed)	Limited due to lack of info on credibility, limited discussion of clinical implications
Lee, Choi, Chan, Chan & Ng, 2009	Yes	Yes	Can't tell (No justification for design)	Yes	Yes	No	Yes	Yes	Yes	Valuable contribution, clear clinical implications
McCarthy, 2007	Yes	Yes	Can't tell (No justification for design)	Yes	Can't tell (Too little info to judge)	No	Can't tell (Too little info to judge)	Can't tell (Too little info to judge)	No (Credibility not addressed)	Limited due to lack of info on credibility
Peddie, Teijlingen &	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable contribution, clear clinical

Bhattacharya 2005										implications
Su & Chen, 2006	Yes	Yes	Can’t tell (No justification for design)	Can’t tell (Too little info to judge)	Can’t tell (Too little info to judge)	No	Can’t tell (Too little info to judge)	No (poor links between results and claims)	No (Credibility not addressed)	Limited due to lack of info on credibility, poor justification for claims
Vogsten, Svanberg & Olsson, 2010	Yes	Yes	Can’t tell (No justification for design)	Yes	Yes	No(researcher known to some participants but not explored)	Yes	Can’t tell (Too little info to judge)	Yes	Valuable contribution to understanding of gender differences
Wirberg, Moller, Hogstom, Tronstad & Lalos, 2007	Yes	Yes	Can’t tell (Don’t specify method)	Yes	Yes	No	Yes	Can’t tell (Too little info to judge)	Can’t tell (clear presentation of findings but little reference to credibility)	Valuable contribution to literature on long term adjustment to childlessness, although hampered by lack of info to judge credibility

Appendix B – Ethical Approval Form

UNIVERSITY OF HERTFORDSHIRE

HEALTH AND HUMAN SCIENCES

ETHICS APPROVAL NOTIFICATION

TO	Louise Hesselvik
CC	Dr Helen Ellis-Caird
FROM	Dr Timothy H Parke, Social Sciences, Arts and Humanities
DATE	12/08/16

Protocol number: **LMS/PGR/UH/02464**

Title of study: Life after infertility; A grounded theory of moving on from unsuccessful fertility treatment

Your application for ethics approval has been accepted and approved by the ECDA for your School.

This approval is valid:

From: 12/08/16

To: 01/12/16

Please note:

If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and your completed consent paperwork to this ECDA once your study is complete.

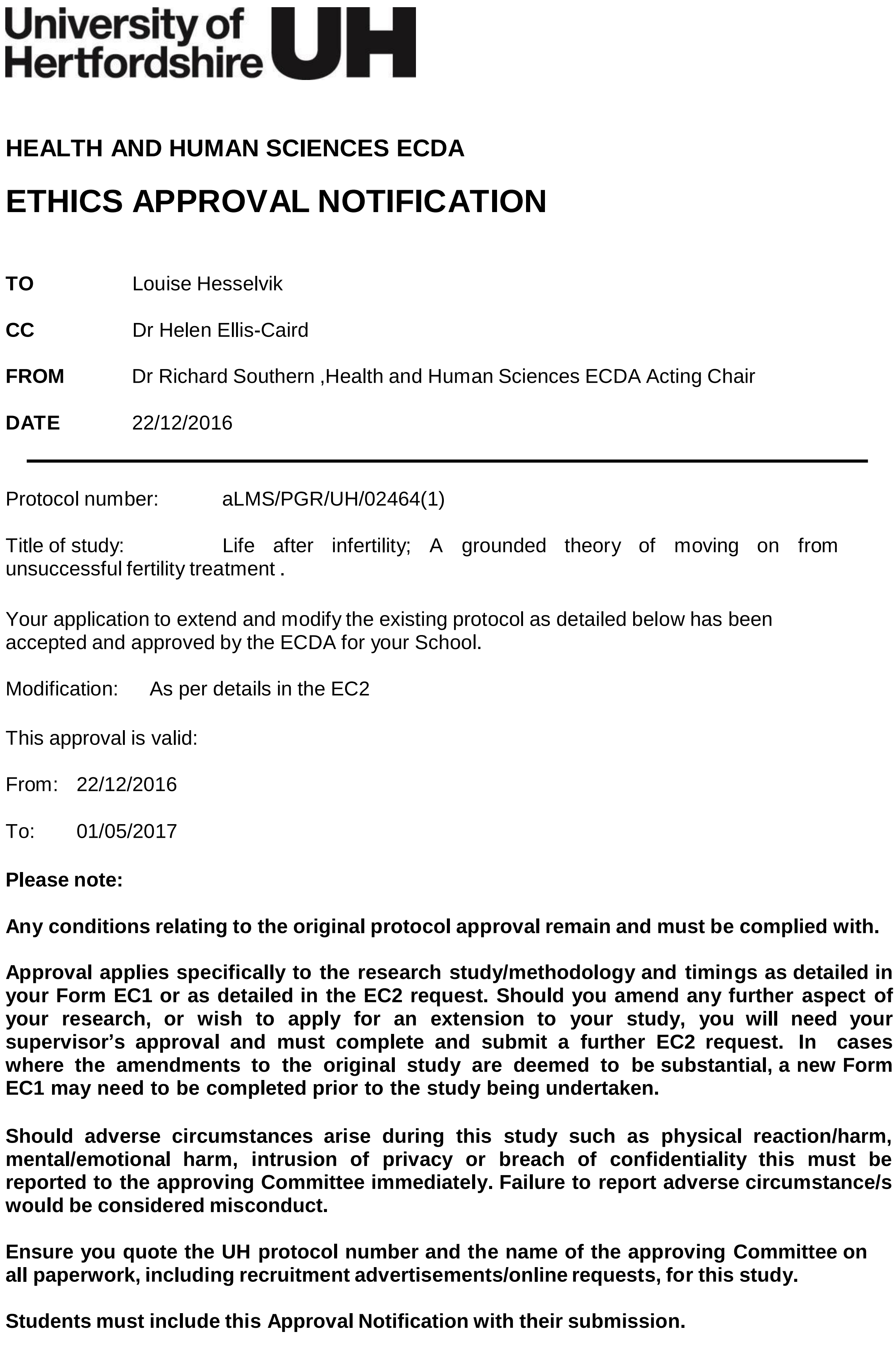
Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1. Should you amend any aspect of your research, or wish to apply for an extension to your study, you will need your supervisor's approval and must complete and submit form EC2. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1 may need to be completed prior to the study being undertaken.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately. Failure to report adverse circumstance/s would be considered misconduct.

Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Students must include this Approval Notification with their submission.

Appendix C – Ethical Approval Form for Amendments



University of Hertfordshire UH

HEALTH AND HUMAN SCIENCES ECDA

ETHICS APPROVAL NOTIFICATION

TO	Louise Hesselvik
CC	Dr Helen Ellis-Caird
FROM	Dr Richard Southern ,Health and Human Sciences ECDA Acting Chair
DATE	22/12/2016

Protocol number: aLMS/PGR/UH/02464(1)

Title of study: Life after infertility; A grounded theory of moving on from unsuccessful fertility treatment .

Your application to extend and modify the existing protocol as detailed below has been accepted and approved by the ECDA for your School.

Modification: As per details in the EC2

This approval is valid:

From: 22/12/2016

To: 01/05/2017

Please note:

Any conditions relating to the original protocol approval remain and must be complied with.

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1 or as detailed in the EC2 request. Should you amend any further aspect of your research, or wish to apply for an extension to your study, you will need your supervisor's approval and must complete and submit a further EC2 request. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1 may need to be completed prior to the study being undertaken.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately. Failure to report adverse circumstance/s would be considered misconduct.

Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Students must include this Approval Notification with their submission.

Appendix D – Participant Information Sheet

UNIVERSITY OF HERTFORDSHIRE
ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS
('ETHICS COMMITTEE')

EC6: 'PARTICIPANT INFORMATION SHEET'

Title of study: *Life after infertility; A grounded theory of moving on from unsuccessful fertility treatment*

Hello. My name is Louise Hesselvik and I am a trainee clinical psychologist at the University of Hertfordshire. I would like to invite you to take part in a study exploring women's experiences of moving on from unsuccessful fertility treatments.

Before you decide whether you would like to take part, it is important that you understand the research that is being done and what your involvement will include. Please take the time to read the following information carefully. Do not hesitate to ask me anything that is not clear about or for any further information you would like to help you make your decision.

What is the purpose of this study?

This aim of this study is to gain insight into women's experiences of coping with unsuccessful fertility treatments. I am particularly interested in understanding more about the decision making process around ending treatment, and the factors which have helped women in the transition from trying to become pregnant to pursuing a life without biological children of their own.

So far studies have focused on the stress of fertility treatment cycles and the impact of difficulties conceiving on women's psychological wellbeing. However, more information is needed regarding how women are able to cope with these stressors and exit the cycle of repeated conception attempts when treatment has not been successful. It is hoped that an increased understanding of women's experiences of coping with unsuccessful fertility treatments can help guide health professionals in how best to support this group of women.

Do I have to take part?

It is completely up to you whether or not you decide to take part in this study. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Agreeing to join the study does not mean that you have to complete it. You are free to withdraw up to 3 months after the interview has been conducted without giving a reason.

Are there any age or other restrictions that may prevent me from participating?

You are eligible to take part in the study if you are 18 or over, if you have tried fertility treatments in the past, but have now decided to stop pursuing treatment.

What will happen to me if I take part?

If you agree to take part in the study, we will arrange an interview at a time and place that is convenient for you. Interviews can take place in person, over the telephone, or via Skype. It is anticipated the interview will last for approximately 60 minutes.

I will ask you some questions about your experience of fertility treatments, how you made the decision to stop treatment, and how you have experienced the adjustment of no longer pursuing treatment. However, it is completely up to you how much you would like to share.

The interview will be recorded and then transferred to a password protected memory stick and kept securely for the duration of the study.

What are the possible disadvantages, risks or side effects of taking part?
The interviews may touch upon sensitive issues which some participants could find distressing. Please know that that you are under no obligation to discuss anything you are not comfortable sharing, and that the interview could be brought to end at any point should you wish.

What are the possible benefits of taking part?
By participating in this study you will contribute to a better understanding of the factors which help women coping with unsuccessful fertility treatments and those who are involuntarily childless. It is hoped that this information can help guide health professionals in how best to support this group of women.

How will my taking part in this study be kept confidential?
All the data collected in this study will be anonymized, meaning all personal information like name and address will be kept confidential to ensure participants are not identifiable. The results of the study are intended to be published and anonymized quotations from your interview may be included, but will not include any identifiable information.

What will happen to the data collected within this study?
Recordings and transcribed interviews will be stored electronically, in a password-protected environment, for the duration of the study. After the completion of the study they will be destroyed under secure conditions. The data will be anonymised prior to storage.

Will the data be required for use in further studies?
It is possible that data from this study will be used in future research for up to a period of 5 years upon completion of the present study. If the data is used, anonymity and confidentiality will be maintained. After a period of 5 years the data will be destroyed.

Who has reviewed this study?
This study has been reviewed and approved by the University of Hertfordshire (School of Psychology) Ethics Committee and secondary registration has been approved by the Research Degrees Board at the University of Hertfordshire.
The UH protocol number is LMS/PGR/UH/02464

What happens next?
If you decide, after reading this information and asking any questions that you may have, that you would like to take part in the study we can arrange a convenient time for the interview to take place. I will also ask you to read and sign a consent form and provide some basic demographic information about yourself.

Who can I contact if I have any questions?

Name: Louise Hesselvik
Email address: [redacted]
Telephone number: [redacted]
Address: Doctor of Clinical Psychology Training Course, University of Hertfordshire, College Lane, Hatfield, Herts, AL10 9AB.

Although we hope it is not the case, if you have any complaints or concerns any aspect of the study, please write to the University Secretary and Registrar

Appendix E – Consent Form

UNIVERSITY OF HERTFORDSHIRE
ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS
('ETHICS COMMITTEE')

CONSENT FORM EC3

Project Title: *Life after infertility; A grounded theory of moving on from unsuccessful fertility treatment*

Statement by Participant

1. • I confirm that I have read and understand the information sheet for this study
2. • I understand what my involvement will entail and any questions have been answered to my satisfaction
3. • I understand that my participation is entirely voluntary, and that I can withdraw up to 3 months after the interview has been conducted
4. • I understand that all information obtained will be confidential
5. • I agree that research data gathered for the study may be published provided that I cannot be identified as a subject
6. • Contact information has been provided should I wish to seek further information from the investigator at any time for purposes of clarification
7. • I have been told how information relating to me (data obtained in the course of the study, and data provided by me about myself) will be handled: how it will be kept secure, who will have access to it, and how it will or may be used.

Participant's Name ……………………………..............

Participant's Signature …………………………………….. Date …………………………………..

Statement by Researcher

- I have explained this project and the implications of participation in it to this participant without bias and I believe that the consent is informed and that they understand the implications of participation.

Researcher's Name ……………………………..............

Researcher's Signature ……………………………………. Date …………………………….

Appendix F – Debrief Form

Title of study: *Life after infertility; A grounded theory of moving on from unsuccessful fertility treatment*

Dear participant,

Thank you for taking part in this study. If you have any questions about this research, please feel free to contact me. Following our interview/the focus group, you may feel you would like to speak with someone or gain some support. The following websites offer advice and support:

http://www.infertilitynetworkuk.com/
http://www.fertilityfriends.co.uk/forum/index.php
https://healthunlocked.com/moretolifeuk
http://www.thedovecote.org
http://www.lesleypyne.co.uk

Please speak with your GP if you feel you would benefit from talking to a professional about any difficulties. They should be able to refer you to local psychological support services. Alternatively, visit http://www.counselling-directory.org.uk/ for a list of private therapists in your area.

Thank you again for taking the time to participate in this study.

Sincerely,

Louise Hesselvik

Email address: [redacted]
Telephone number: [redacted]
Address: Doctor of Clinical Psychology Training Course, University of Hertfordshire, College Lane, Hatfield, Herts, AL10 9AB.

Appendix G – List of Websites and Facebook Groups Used for Recruitment

https://healthunlocked.com/moretolifeuk

https://www.facebook.com/moretolifeuk

http://www.thedovecote.org

https://www.facebook.com/LesleyPyneCoach/

Appendix H – Interview Guide

Preliminary Interview Guide

*Participant will complete brief questionnaire prior to start of interview.

Please note that formal questions are listed below, bullet points will serve as follow on prompts to be used for further exploration and elaboration.

1.) Making the decision to stop treatment

Q1. You've detailed in your questionnaire quite a number of treatments that you have undergone over time. I wonder when it was that you began to think about stopping treatment?

- Why did you decide to stop pursuing treatment at this time?

Q2. Can you tell me a little bit about the process you went through in deciding to stop treatment?

- Was there a period of going back and forth about your decision?
- Was it your decision alone? Did your partner, friends, family, medical team influence the decision?
- Anyone or anything that was particularly helpful or unhelpful in decision making process (ie. professional medical advice, professional psychological support, advice from friends or family, other?)

2.) Impact of decision

Q3. What did the decision to stop treatment mean to you at the time; did you see it as a temporary break from treatment but you thought you would start again, were you planning to explore other avenues of becoming a parent, or did you view stopping treatment as a decision to stop pursing the goal of becoming a parent?

3.) Current circumstances

Q4. Do you think you might pursue further treatment in the future? Are you still trying to become pregnant?

Q5. On websites such as X, there are several terms that people use to describe themselves, for example, childless, childless by circumstance, childfree. How do position yourself in relation to these terms?

4.) Looking back

Q6. Is there any type of support or advice that you think would have been helpful for you in the process of deciding to stop fertility treatment? Have you used anything that was helpful (internet, support groups, yoga, professionals etc?)

Q7. Based on your experience, what advice would you give to women currently in the cycle of ongoing treatment and who are considering stopping treatment?

5.) Check in

Q8. Is there anything I have not asked about that you would like to share?

End of interview/debrief

- What was experience of talking today like for you? Check in about emotional state, discuss how to access support should they wish to
- Opportunity for participant to ask any questions about research.
- Share contact details, confirm arrangements if participants would like summary of results.

Appendix I – Participant Survey

Participant questionnaire

Name: ………………………………………….

Age: ……………………………………......

Ethnicity: ………………………………….........

1.) In the space below, could you please describe the *types* of fertility treatments you have tried in the past?

……

……

……

……

2.) For how long did you pursue fertility treatment?

……

……

3.) When did you decide to stop pursuing fertility treatments (how long ago was this)?

……

……

Appendix J – Research Diary Excerpt

Research diary 22/9/16

2rd interview completed. Met with Helen and Carla to show transcripts. Both participants have been really positive so far about experiences, Carla seemed a bit surprised about this, didn't seem to match up with her experience of clients she sees. Made me think about what participating in a study like this might evoke in participants, also the title of the study - life after infertility. It's almost asking participants, how is your life? Of course they will want to present positive version of this, but wonder if I'm getting the whole story. Helen and Carla had some ideas about how I might be able to ask questions which make it feel more safe for participants to speak a bit more about more difficult aspects of their experience - waves of sadness stuff. Noticing I'm still feeling that I have to (or just think I have to and jump into) defending why I'm doing this study. I feel voyeuristic somehow, perhaps because I don't have experience of infertility.

Research diary 17/11/16 – 'It felt like therapy'

P5 said this at when I asked how she found the interview, and others have alluded to it. It feels like good thing in one sense that the interviews have seemed to be really helpful for participants. Something which maybe they have had few opportunities to reflect on with anyone – aid to with processing, sense making. However, also very aware that I sometimes fall into trying to aid in seeing the positives, reframing, therapizing in room. I obviously feel very uncomfortable with just letting things be a bit crap, or sad.

Research diary – 14/12/16

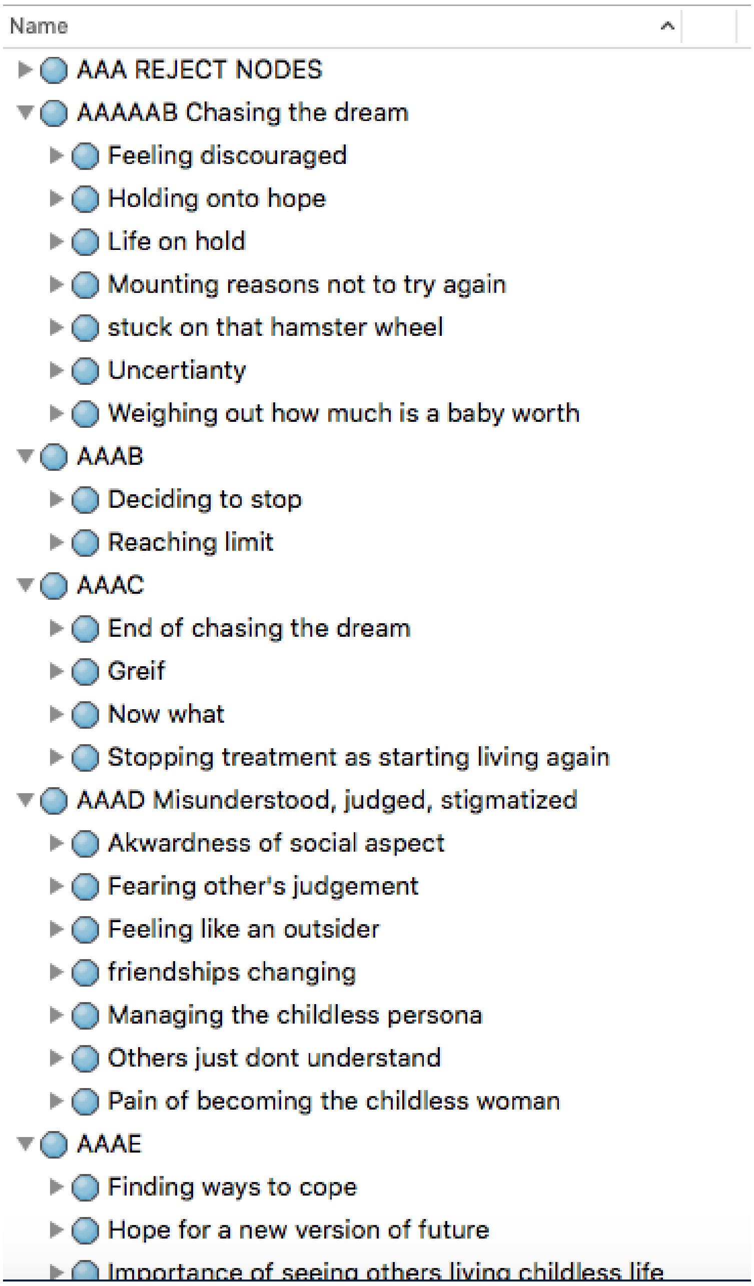
Been hearing a lot about how friends and family don't really 'get it' say the wrong thing, how awkward social side of this can be. I think this has been part of my anxiety, not wanting to be part of unhelpful 'other' – pitying, or saying the wrong thing. Feel like not I'm not an 'insider', and therefore a potential threat somehow. Reminds me of reciprocal roles in CAT. Think this has changed over the course of the interviews, I feel that now that I do understand something about participants' experiences, this element of the interviews feel a bit different, feel less anxious about getting it wrong. Seems to be a parallel process here of what happens with friends family when they have someone they love struggle with infertility/childlessness, perhaps pull away for fear of getting in wrong. However, through understanding and getting close that anxiety goes away.

Appendix K – Sample of Line by Line Coded Transcript

P 1 Transcript	Initial Codes	Notes
[redacted]	[redacted]	[redacted]
[redacted]		
[redacted]	[redacted]	
[redacted]		
[redacted]	[redacted]	
[redacted]		
[redacted]	[redacted]	
[redacted]		
[redacted]	[redacted]	[redacted]
[redacted]		
[redacted]	[redacted]	
[redacted]		
[redacted]	[redacted]	
[redacted]	[redacted]	

[redacted]	[redacted]	[redacted]

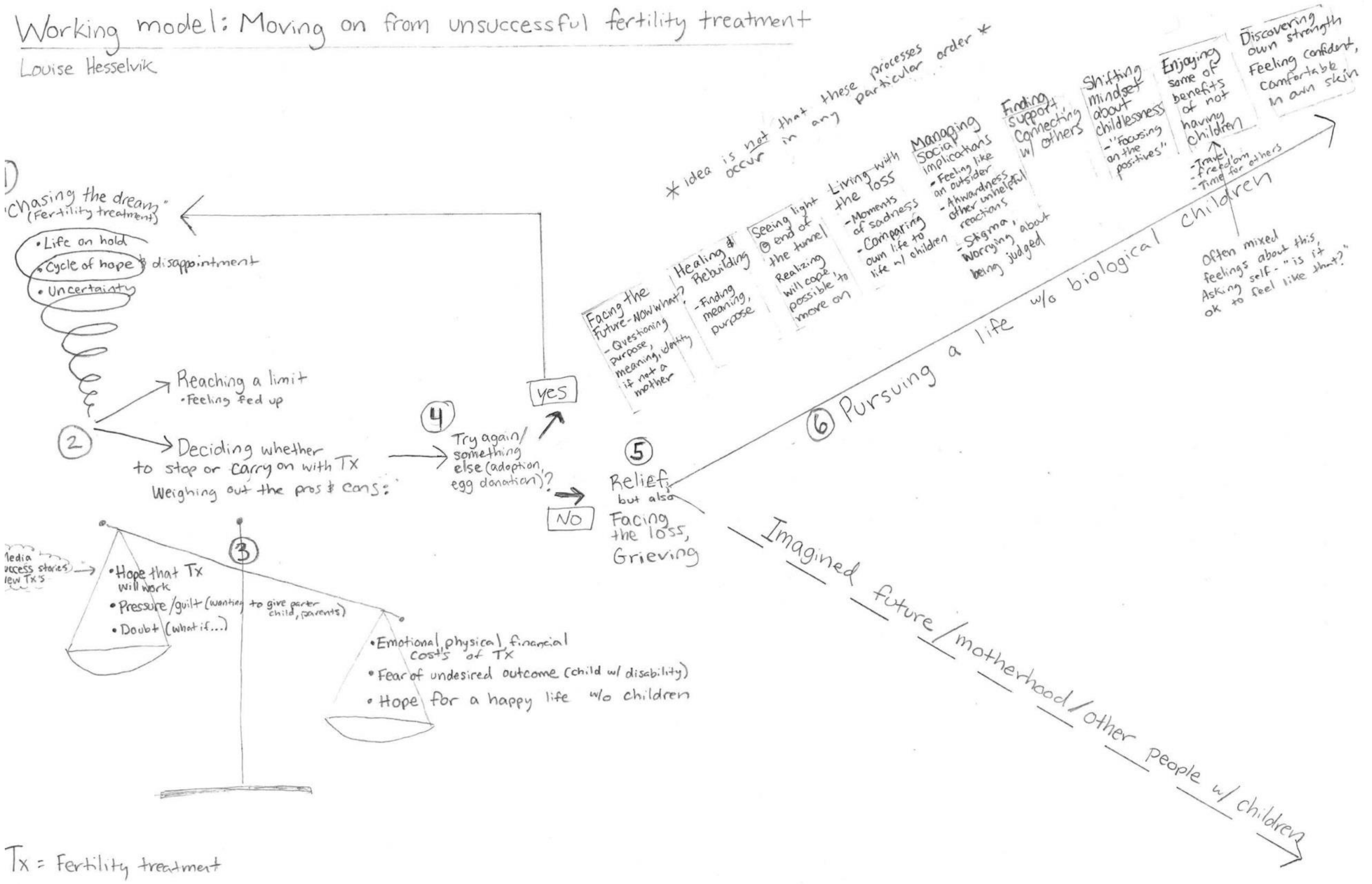
Appendix L – Sample of Clustered Focused Codes in NVivo/ Process of Category Development



Name

- AAA REJECT NODES
- AAAAAB Chasing the dream
  - Feeling discouraged
  - Holding onto hope
  - Life on hold
  - Mounting reasons not to try again
  - stuck on that hamster wheel
  - Uncertianty
  - Weighing out how much is a baby worth
- AAAB
  - Deciding to stop
  - Reaching limit
- AAAC
  - End of chasing the dream
  - Greif
  - Now what
  - Stopping treatment as starting living again
- AAAD Misunderstood, judged, stigmatized
  - Akwardness of social aspect
  - Fearing other's judgement
  - Feeling like an outsider
  - friendships changing
  - Managing the childless persona
  - Others just dont understand
  - Pain of becoming the childless woman
- AAAE
  - Finding ways to cope
  - Hope for a new version of future
  - Importance of seeing others living childless life

Appendix M – Early Draft of Theoretical Model



Appendix N – Table of the Progression of Category Development

Core Categories	Superordinate Categories
Living in limbo	Weighing up: Hope
	Weighing up: Reasons to stop treatment
Leaving treatment	Reaching a limit/ deciding to stop
	Dream dying, loss hitting
Learning to live with involuntary childlessness	Facing a crisis of meaning, self image, and belonging
	Resolution: Finding a way to live

Superordinate Category	Category	Focused code	Example of quotations making up code
Weighing up: Hope	Hope	Feeling certain treatment will work	*It doesn't occur to you…you know that it might not work but you have to go in... I kind of liken to a… it's a like sitting an exam or something. You might fail but you have to assume that you're going to pass. - P2*
		Another chance to make it happen	*In his mind we had another chance to make it happen" - P3*
		Longing for a baby/ to be a mother	*I didn't care what else happened in my life but I wanted to be a mum - P7*
Weighing up: Reasons to stop	Financial costs	Financial costs	*They said, look you can have another go, but it will, you know, cost you. So money was a factor as well. Um, and they said you know it could work, it might not work, so it's like well this is a pretty big gamble really - P4*
	Physical costs	Physical costs	*After the last four I felt quite physically unwell, and I kind of felt like what am I doing? What am I doing to my body really? - P3*
	Emotional costs	Cycle of hope and disappointment	*in my heart hoped it would work, but my head was saying this this this, so knew I had to psych myself up, which is hard, because It's a hard merry go round to jump off of - P9*
		Life on hold	*We had a year's break, just because I couldn't deal with it, because my life had been on hold for nearly seven years. - P8*
Reaching a limit/deciding to stop	Reaching a limit	Reaching a limit	*They did say something that struck a chord, and it helped us, they said: "you've had enough." And it was like, yeah, we have. And they said don't feel bad about that. That's fine. You need to move on. And it was, "yeah. We've had enough now - P4*
	Deciding to stop	Being practical about when to stop	*I think when we realised it hadn't worked, it was that point when we thought, right,*

			we've tried everything we think we can. we just had to be practical and it was like, that's it then, you know. - P4
		Deciding by putting off	*We just sort of stopped talking about it - P2*
		Drawing a line in the sand	*We were just - that's it lets draw a line under the whole thing. a bit of a shock to the system to actually draw that line. - P5*
Dream dying, loss hitting	Dream dying, loss hitting	End of chasing the dream	*It was a weird time…it was this period of my life, with the babies and stuff...was finished - P5*
		Facing loss	*Facing that loss and building myself up again after that loss...erm....it was...there is nothing else that can happen to me that's as bad as that - P7*
		Just getting through	*At that time hard for me to think about anything outside that box of grief really - P9*
Facing a crisis of meaning, identity, and belonging	Facing a threat to purpose and meaning	Questioning purpose of life	*We're at a point now where we can do what we want to a certain extent. But I just feel, how long is it going to last before we feel , we've been there, we've done that, we've seen this. I am a bit fearful of finding that purpose again - P12*
		Threat to meaning/ Why me?	*You know... you're told when you go to IVF, right don't, don't, don't smoke, you know constant, look at your weight, and all of that. And you're surrounded by people who are pregnant and... you know, going out for a fag, they're overweight, all of it, you know? And you just think: where's, where's the justice in this? - P4*
	Facing a threat to identity and self image	Feeling like a failure	*I see us not having biological children as a massive failure. And I know it's not our fault, - P12*
		Fearing judgment, feeling stigmatized	*As a woman I feel very...I feel we're very judged – P7*
	Facing a threat to sense of belonging	Feeling like an outsider	*And if I see people with children who aren't in my friendship circle or in my family, I almost try and make excuses for how they might be rather than how I am because I almost feel like I don't fit in so I've got to try even harder - P7*
		Others just don't understand	*My mum...who's probably the most difficult person in the whole, in my whole relationship. erm...she was just like, oh - adopt. That's her answer - just adopt. Friends, erm...it varied really. Erm....i think the ones that stick in my head are the ones that just don't really understand IVF. They don't understand what you have to do to yourself, the financial aspects. So they were like, but why are you stopping? Just carry on. - P3*
Resolution: Finding way to live	Time	Time heals	*My friend's mum died..[….]..and she said to me 'you always carry a rugsack of life's burdens but the longer you carry the rugsack, typically, the lighter it feels because you've got so used to carrying it'. I think that's actually a very helpful way of looking at it.- P9*

		Learning to live with sadness	*If I'm feeling these emotions, and if I need to cry, I'll cry. But that, it, that becomes less, less, I've had so... far less moments, compared to, say, three years ago. - P8*
	Reframing childlessness	Silver-linings; focusing on the positives	*On the positive side ... we kind of think, as a couple, maybe it's fate that we didn't have children, and kind of relieved we didn't, you know. Because we've got plenty of nephews, nieces and god-children, and we see friends go through it, and all of this, have families... and we kind of think: it's just us, we don't have to worry about anybody else, you know. And it's quite nice. - P4*
		Reframing childlessness	*I mean, my identity is, kind of, because of the work I do now, supporting people who can't have children, you know, my identity is the fact that I'm childless. However, it's not a negative thing. Whereas before it was kind of a really negative, I felt very toxic, I felt very shamed - P8*
	Taking action	Making life changes as symbols of moving on	*I moved house, which took a really long time but I took me to a place where I was ready to move house and was ready to…to move on really - P9*
		Finding alternative sources of meaning	*We had a dog who...the image that was conjured up with animals and child substitute was always a bit odd, but I do think they are child substitutes but not in the way that people who don't understand would say that. but you need to look after something. you need to be responsible for something, or somebody. and it's good to have that somebody at home. and they are great children because you don't have to put them into a cresh or anything! - P6*
	Peer support	Connecting with other childless women	*And I definitely find solace in other woman who who are of similar age and are not going to have children - P2*
		Sisterhood	*On mothers day, 1'clock, will all think of each other… so we have that comradery, bond, whatever you want to call it - P9*

Appendix O – Excerpt of Memos

Memo 17/11/16 Relationship with being in out-group

Lots of participants have spoken about feeling like an ‘outsider’. Discussed this with Helen last week, and spoke about theme of discrimination and stigma. Spoke about how groups can turn stigmatized identity into a positive thing (like gay pride), but issue with childlessness is that these women may not themselves view their difference as positive thing. Being an outsider came up in interview with P6 today, asked her about whether this was first time in her life she had felt like outsider. This seemed to really touch a nerve (not it a bad way). Made me realized people come to this with such different histories – so of course what childlessness triggers off for them will be different. Also wonder if some people more comfortable or less comfortable with being in out group, perhaps someone who has always felt a bit different used to this. For P6 seemed to be the opposite – wish for motherhood to heal feeling of being different in the past.

Memo 5/12/16 Gambling

Some women have spoken about being on the ‘hamster wheel’ of treatment. Their life is on hold, but they want to try just once more in case it works. This reminds me of being a gambler, one more roll of the dice might bring the big win, but every time the debts are mounting. Physical, emotional and financial costs are mounting, and life is getting worse, so the thought of just ending up with that life, without the prize (baby) must feel intolerable. At the same time, the things that might make life worth living (putting energy into other things), likely things that feel impossible to focus on when you are in treatment – no time, money, energy to invest in anything else. Under these circumstances it’s understandable that actually making the decision to stop treatment extremely difficult.

Memo – 14/12/16 Shifting mindset

Shifting mindset about childlessness seems to be a really important part of coping. Lots of suggestions in interviews so far of reframing, choosing to look at positives, examples of therapies that participants found helpful (CBT, EFT, NLP etc etc.). Reminds me of the idea of cognitive dissonance, that if you can’t change circumstances or environment, change how you think about it instead.

Memo 20/12/16 Pain of becoming a childless woman. Reluctantly accepting childless identity.

Stopping treatment seems to not just be about letting go of imagined child, imagined life with child, but also of reluctantly taking on identity of childless woman. Identity which seems to be really stigmatized in our society. P8 described feeling like not being a mother made her “toxic” “shameful”, seems to call for something very strong to break that association with childlessness. Imagine if word “widow” was stigmatized in this way, or we shamed parents who had lost a child. Seems experience of childlessness about grief, but grief with added complications – invisible, misunderstood, somehow in your control, open ended, and socially shameful. Stopping treatment as starting living again, but also starting living a life hadn’t planned for, with identity that you don’t want – as childless woman. Seems to link to ‘shifting mindset’, but actually more about need to reframe what it means to be childless woman – break from social narrative about this as negative thing and reject a more stigmatized view of childlessness.

Memo 27/2/17 Wound healing

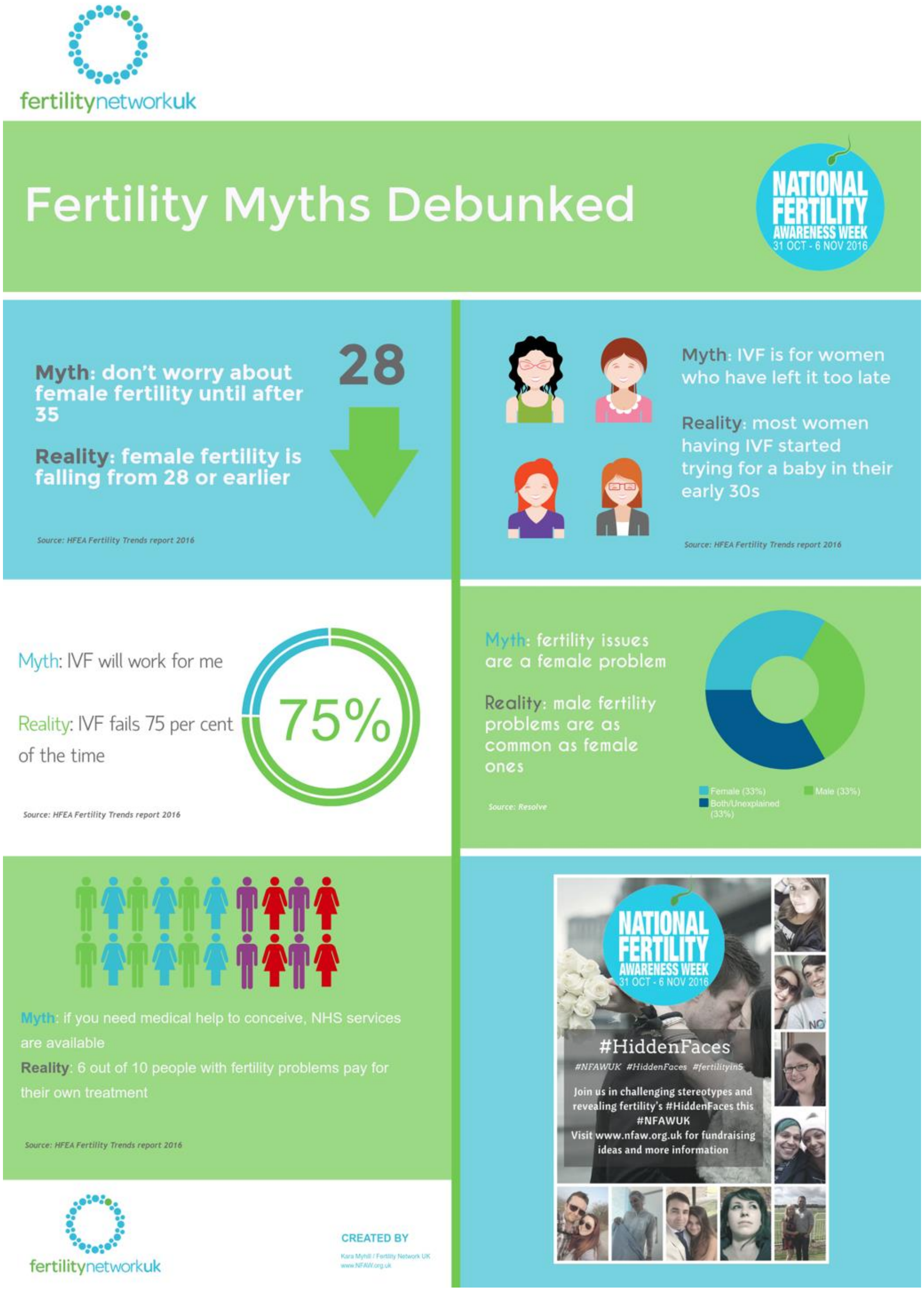
I have the imagine in my head of being in treatment like keeping a space open for a child, in case they come along. Problem is, there is a sense of something missing, almost like an open wound. Moving on means filling that with something else, healing, but more you do that less room there is anymore for a child. Why maybe difficult down the line to consider adopting etc. Like a puzzle, if missing you re-shuffle to adapt to the loss. Whilst in treatment don’t re-shuffle around the missing piece. Frozen.

Appendix P – Quality Criteria Table

Quality control criteria	Description of criteria/means for achieving criteria	What I did to meet criteria	Example
1. Worthy topic	The topic chosen for research is relevant, timely, significant, interesting	- Little known area, few studies in literature - Growing population of women seeking fertility Tx and affected by Tx failure - Liaised with clinical psychologist working in field about relevance of study - Aim to generate new theoretical understanding through GT	Pg.31-32 Discussion of rational
2. Rich rigor	Sufficient richness and abundance of data sources, samples. Rigorous data analysis procedure which is sufficiently complex and in-depth to be able to describe phenomena being studied	- Enough data to support claims, 9 in-depth interviews, focus group, diverse sample with respect to age/time since Tx - Time in field; data collection/analysis spread over 7 months - Procedures including research diary memos aided thorough and thoughtful reflection about data - Data trail to substantiate claims	Pg. 43 - 45 discussion of data analysis process Pg. 107 - 113 for data trail
3. Sincerity	Self-reflexivity about researcher's biases, goals. Honesty, transparency about research process including mistakes	- Reflections on my own subjective feelings, sense making, point of view through research diary - Written reflections and discussions with research supervisor about why I am doing this study, how process has impacted my views, ways I might be influencing conclusions reached through data analysis - Detailed account of data collection/ transparency about data analysis process	Pg. 41 -42 for example Pg. 103 for research diary
4. Credibility	Study demonstrates trustworthiness and plausibility of research findings	- Thick descriptions – abundant concrete details and examples to back up claims - Variable sources of data (interviews and focus group) to increase scope and depth of understanding -Member reflections to gain feedback on my reflections	Pg. 51 -52 for example of data (participant quotations) to back up claims
5. Resonance	Study's ability to influence or move reader by presenting text which is clear, evocative, and promotes empathy and identification. Study's ability to generate knowledge resonance for different contexts, situations, audiences.	- Attempt to share excepts from transcripts which connect to emotion of interviews - Discussion of wider issues of discrimination, stigma of childlessness, cultural views on what is 'legitimate' loss, which might have wider resonance that solely the population being studied	Pg. 79 for example
6. Significant contribution	Study makes important contribution to the field by improving/extending knowledge, theoretical understandings, or clinical practice	- Study generated new conceptual understandings which may help to inspire new research - Generated new theoretical model with practical applications for clinical practice	Pg. 77-79 for clinical implication

7. Ethics	Adherence to professional/research ethics guidelines, responding ethically to issues which arise in research process	- Applied to UH ethics board - Researcher carefully considered potential distress with clients, conducted debrief, offered information for access to support - Responded to ethical considerations as they arose in the field	Pg. 36 -37 for ethical considerations
8. Meaningful coherence	Whether study achieves its stated aims. Coherence between epistemological position of research and research design, data collection, and analysis	- Discussion of how results meet research aims - Epistemological position presented in relation to research design, exploration of social construction of infertility	Pg. 9 For epistemological stance discussion of social construction of infertility

Appendix Q – Fertility Network Leaflet



fertilitynetworkuk

Fertility Myths Debunked

NATIONAL FERTILITY AWARENESS WEEK
31 OCT - 6 NOV 2016

28

Myth: don't worry about female fertility until after 35

Reality: female fertility is falling from 28 or earlier

Source: HFEA Fertility Trends report 2016

Myth: IVF is for women who have left it too late

Reality: most women having IVF started trying for a baby in their early 30s

Source: HFEA Fertility Trends report 2016

Myth: IVF will work for me

Reality: IVF fails 75 per cent of the time

75%

Source: HFEA Fertility Trends report 2016

Myth: fertility issues are a female problem

Reality: male fertility problems are as common as female ones

Female (33%)
Male (33%)
Both/Unexplained (33%)

Source: Resolve

Myth: if you need medical help to conceive, NHS services are available

Reality: 6 out of 10 people with fertility problems pay for their own treatment

Source: HFEA Fertility Trends report 2016

NATIONAL FERTILITY AWARENESS WEEK
31 OCT - 6 NOV 2016

#HiddenFaces

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