Exploring the subjective experiences of fertility preservation among cancer survivors in South Africa

Charlene Purdy

Thesis presented in fulfilment of the requirements for the degree of Master of Arts in Psychology in the Faculty of Arts and Social Sciences at

Supervisor: Dr R. Roomaney

December 2022

DECLARATION

By submitting this thesis, I declare that I understand what constitutes plagiarism, that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third-party rights, and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

Date: December 2022

ABSTRACT

Infertility is one of the most concerning side-effects of cancer treatment for both men and women of reproductive age and intend starting or expanding their family. Recent medical advances provide oncology patients who are at risk of infertility the opportunity to preserve their biological material for future use. A vast amount of literature can be found on the medical aspects of fertility preservation in non-cancer patients; however, little research exists that explore the subjective experience of fertility preservation of oncology patients. Furthermore, no research has been conducted or documented in South Africa on this phenomenon.

This study explored the subjective experience of fertility preservation among 10 female oncology patients who underwent fertility preservation prior to commencing with their cancer treatment. Participants were recruited from private fertility clinics either in Johannesburg or Cape Town. Semi-structured, in-depth individual interviews were conducted, and the data were analysed using thematic analysis. The themes derived from thematic analysis were then conceptualised with the use of The Health Belief Model. Five themes and 10 subthemes were developed that provide an understanding on the subjective experience of fertility preservation. The study received ethical clearance from the Health and Research Ethics Committee (HREC) at Stellenbosch University.

The findings of this study suggest that psychological and emotional strain accompany a cancer diagnosis. The process of fertility preservation was met with a variety of emotional, cognitive, physical, and social challenges. Despite the challenges hormone treatment posed, the women reported gratitude and hope in the face of their cancer journey. The lack of information, costs and potential risks associated with fertility preservation was a concern for several women, however, all the women underwent fertility preservation and reported overall positive experiences. It is recommended that more research is conducted on the barriers and facilitators of fertility preservation using a larger sample and with patients who did not take up or fertility preservation.

Keywords: Fertility preservation, cancer, infertility, artificial reproductive technology, motherhood, resilience

OPSOMMING

Onvrugbaarheid is een van die mees kommerwekkende newe-effekte van kankerbehandeling vir beide mans en vroue van reproduktiewe ouderdom en wat beplan om hul gesin te begin of uit te brei. Onlangse mediese vooruitgang bied onkologiepasiënte wat die risiko loop van moontlike onvrugbaarheid die geleentheid om hul biologiese materiaal vir toekomstige gebruik te bewaar. 'n Groot hoeveelheid literatuur kan gevind word oor die mediese aspekte van vrugbaarheidsbewaring by nie-kankerpasiënte; min navorsing bestaan egter wat die subjektiewe ervaring van vrugbaarheidsbewaring van onkologiepasiënte ondersoek. Verder is geen navorsing in Suid-Afrika oor hierdie verskynsel gedoen of gedokumenteer nie.

Hierdie studie het die subjektiewe ervaring van vrugbaarheidsbewaring onder 10 vroulike onkologiepasiënte ondersoek wat vrugbaarheidsbewaring ondergaan het voordat hulle met hul kankerbehandeling begin het. Deelnemers is van private vrugbaarheidsklinieke in Johannesburg of Kaapstad gewerf. Semi-gestruktureerde, in-diepte individuele onderhoude is gevoer, en die data is ontleed met behulp van tematiese analise. Die temas wat uit tematiese analise afgelei is, is toe gekonseptualiseer met die gebruik van The Health Belief Model. Vyf temas en 10 subtemas is ontwikkel wat 'n begrip verskaf oor die subjektiewe ervaring van vrugbaarheidsbewaring. Die studie het etiese goedkeuring van die Gesondheid- en Navorsingsetiekkomitee (HREC) by die Universiteit Stellenbosch ontvang.

Die bevindinge van hierdie studie dui daarop dat erge sielkundige en emosionele spanning 'n kankerdiagnose vergesel. Die proses van vrugbaarheidsbewaring is met 'n verskeidenheid emosionele, kognitiewe, fisiese en sosiale uitdagings teëgekom. Ten spyte van die uitdagings wat hormoonbehandeling ingehou het, het die vroue dankbaarheid en hoop gerapporteer in die gesig van hul kankerreis. Die gebrek aan inligting, koste en potensiële risiko's verbonde aan vrugbaarheidsbewaring was 'n bekommernis vir verskeie vroue, maar al die vroue het vrugbaarheidsbewaring ondergaan en algehele positiewe ervarings gerapporteer. Dit word aanbeveel dat meer navorsing gedoen word oor die hindernisse en fasiliteerders van vrugbaarheidsbewaring deur 'n groter steekproef te gebruik en met pasiënte wat nie opgeneem het nie of vrugbaarheidsbewaring.

Sleutelwoorde: Vrugbaarheidsbewaring, kanker, onvrugbaarheid, kunsmatige voortplantingstegnologie, moederskap, veerkragtigheid

ACKNOWLEDGMENTS

Firstly, I would like to show my gratitude and appreciation to my supervisor, Dr Rizwana Roomaney. Thank you for your guidance, support, encouragement, and patience from the beginning of this journey, I will forever be grateful. Thank you for all the effort and energy that you have put into this study. It was a privilege to be taught and supervised by you!

I would like to thank both the staff and doctors from Aevitas and Vitalab that assisted me in this study by recruiting participants and for allowing me to conduct my interviews at the clinic.

I would like to thank all the women that participated in the study. Thank you for sharing and trusting your stories with me, it was very insightful and will contribute greatly to this field of study. Without you none of this would have been possible.

To my partner, thank you for all the love, support, and encouragement during the last few years.

Lastly, but most important, I would like to thank my sister, parents, family, and friends for all the love, support, and encouragement you provided me during this time. To my uncle who passed away before I could finish and share this moment with you, your support and encouragement was always much needed and appreciated.

Table of Contents

LIST OF TABLES

GLOSSARY OF TERMS

Anger: An emotion characterized by antagonism toward someone or something you feel has deliberately done you wrong.

Anxiety: Intense, excessive, and persistent worry, nervousness, and fear about everyday situations. Fast heart rate, rapid breathing, sweating, and feeling tired may occur.

Artificial reproductive technology (ART): Surgical and medicinal fertility treatment procedures such as in vitro fertilization (IVF), artificial insemination (AI), intracytoplasmic sperm injection (ICSI) and/or the handling of gametes, embryos, and sperm.

Cancer: A presence of abnormal cells within the human body that grows, infiltrates, and affects certain parts of the human body and could be fatal.

Cancer remission: When the number of cancer cells or tumour size has decreased, the signs and symptoms have lessened or are undetectable, a person is living in remission.

Coping mechanisms: Strategies that people employ (consciously or unconsciously) while facing stress or trauma, which help them manage and adjust to painful or overwhelming emotions while maintaining their emotional well-being.

Depression: A mental health disorder characterised by persistently depressed mood or loss of interest in activities, causing significant impairment in daily life.

Hormone sensitive cancer: A type of cancer (breast and ovarian) that requires and grows with hormone cells within the body (oestrogen and progesterone).

Identity building: A multifaceted development process in which individuals develop a unique view of themselves and their identity, values and morals, personality, and self-concept.

Internalized stigma: Refers to the process where a person with a stigmatized disease applies the negative public stigma associated with the disease to herself.

Infertility: A medical disease of the male or female reproductive system defined by the failure to achieve a pregnancy after 12 months or more of regular unprotected sexual intercourse.

Menopause: A time during which the female body naturally transitions into the end of reproductive years, this normally occurs from the age of 40 and above.

Motherhood: State or experience of being a mother and having or raising a child.

Oncofertility: Medical field that bridges the specialties of oncology and reproductive medicine with the purpose of maximizing the reproductive potential of cancer patients and survivors.

Peripheral T-cell lymphoma (PTCL): Rare and aggressive lymphomas that developed from excessive growth in white blood cells (T-cells), particularly within lymph nodes.

Psychological resilience: The mental and emotional ability to cope with trauma and/or a crisis while attempting to return to status quo (pre-crisis) as soon as possible.

Quality of life: A term used to describe a broader concept that is concerned with the degree to which an individual is comfortable, healthy, and able to fulfil a normal content and balanced life without impairments or limitations.

Reproductive age: Although vague, commonly believed to be from the age of 20 to 49, in which women are actively able to engage in childbearing.

Triple negative breast cancer: A type of aggressive breast cancer with a poor prognosis that is not fuelled by hormones receptors such as oestrogen and progesterone and HER2 protein.

Chapter 1: Introduction, Rationale and Objectives

1.1 Background

Globally cancer is characterized as a complex, and life- threatening disease, affecting one in every five women and one in every six men (Kim, Klemp, & Fabian, 2011; Tschudin & Bitzer, 2009; World Health Organisation, 2018). Recent statistics indicated that globally during 2018, 18.1 million new cases of cancer and 9.6 million cancer-related deaths were reported (World Health Organisation, 2018). The most common cancers found among women in South Africa are haematological cancer, breast cancer, and cervical cancer (Herbst, 2015). Cancers such as breast cancer and cervical cancer peak after the age 50 years, although accounts of women of reproductive age that are diagnosed with cancer are continuously increasing (De Vos, Smitz, & Woodruff, 2014).

Psychosocial oncology research has shown that a significant percentage of cancer patients are confronted with and experience psychological distress during their diagnosis, treatment process and post-treatment (Sostaric & Sprah, 2009; Tschudin & Bitzer, 2009; Warren, Melrose, Brooker, & Burney, 2018; Williams & Jeanetta, 2016). Psychological distress refers to non-specific symptoms of stress, anxiety and depression (Drapeau et al., 2012).

High levels of psychological distress are indicative of impaired mental health and may reflect common mental disorders, like depressive and anxiety disorders. Studies demonstrate that individuals diagnosed with cancer experience symptoms of anxiety (Pandey et al., 2006; Perz, Ussher, & Gilbert, 2014; Perz & Ussher, 2018; Sostaric & Sprah, 2009), depression (Pandey et al., 2006; Perz & Ussher, 2018), and loneliness (Warren, Melrose, Brooker, & Burney, 2016; Warren et al., 2018).

Even though patients with cancer are living longer due to advanced treatment methods developed over the past decades, concomitant treatment side-effects remain a concern

(McLaren & Bates, 2012). Impaired fertility is classified as one of the main side-effects of cancer treatment that affects both women and men (Ronn & Holzer, 2013). Many patients and their families refer to the combination of cancer and possible infertility as a "double jeopardy" (Inhorn et al., 2017). This double jeopardy implies that patients may experience dual trauma, first related to the cancer and then second, related to the possibility of infertility (Ehrbar et al., 2016; Inhorn, Birenbaum-Carmeli, & Patrizio, 2017; Perz & Ussher, 2018).

Infertility is defined as an inability to conceive a child after 12 months of regular unprotected intercourse (McQuillan, Greil, White, & Jacob, 2003). Given the fact that reproduction is a dominating social expectation of women, a cancer diagnosis and infertility may have a negative and distressing effect on women that experience infertility (Avila, 2016). Studies have demonstrated that infertile women experienced greater sensitivity, mood disturbances, hostility, and anxiety compared to fertile women (Croson & Keim-Malpass, 2016; Obeidat, Hamlan, & Callister, 2014; Perz & Ussher, 2018; Zuraida, 2010).

Women who experience cancer prior to, or during their reproductive lifespan may benefit from recently developed assisted reproductive technologies (De Vos et al., 2014; Kim & Jeon, 2012; McLaren & Bates, 2012). Fertility preservation, also known as assisted reproductive technology, consists of a series of techniques that are performed before cancer treatment that provide cancer patients with the opportunity for biological parenthood after treatment. Fertility preservation in women is understood to be more demanding than in men as the treatment process in women is much more complex than men (Perz & Ussher, 2018). Therefore, this study explores the experiences of fertility preservation among women.

1.2 Problem Statement

Cancer continues to place a significant burden on individuals, families, health services, and society (Moodley et al., 2016). According to the World Health Organisation (2018), it is estimated that around 43.8 million people are affected by cancer. Currently, continents such as Africa, Asia, and South America account for 60% of the newly diagnosed cancer cases, and this has been attributed to population growth, ageing, social and economic development (American Cancer Society, 2018).

Cancer is defined as the presence of abnormal cells within the human body that grows, infiltrates, and affects certain parts of the human body (American Cancer Society, 2017; Herbst, 2015; Kim et al., 2011; Warren, Melrose, Brooker, & Burney, 2018). Treatment options for patients with cancer depend on the type and stage of cancer and typically include surgery, chemotherapy, and radiation (David & Orwig, 2017; Lopategui, Yechieli, & Ramasamy, 2017; Pandey et al., 2006). However, chemotherapy and radiation agents may significantly affect patient fertility (Kim, Klemp, & Fabian, 2011; Levine, Canada, & Stern, 2010).

Oncofertility is a new and emerging interdisciplinary field, addressing issues of gonadotoxicity (temporary or permanent damage to ovaries or gametes) associated with cancer therapies and to facilitate fertility preservation (Ronn & Holzer, 2013; Sigismondi et al., 2015). Research on how cancer treatment affects reproductive health, and the number of preservation options are increasing, however, there is still an absence of research with regards to the subjective experiences of fertility preservation (Kim & Jeon, 2012).

Fertility preservation (e.g., gamete freezing) usually takes place prior to the commencement of cancer treatment. In women, this typically results in a two-week delay in cancer treatment (Dayal, 2012). However, patients diagnosed with cancer are often not informed by health practitioners about fertility preservation techniques (Quinn & Vadaparampil, 2013). This may be because oncologists treating cancer patients prioritise cancer treatment to extend patients' life expectancy. However, offering restoration of fertility may greatly enhance individual's psychological quality of life (Tschudin & Bitzer, 2009).

Cancer treatment usually commences immediately after diagnosis, leaving very little time for patients and doctors to consider and discuss fertility preservation (Dyer & Quinn, 2016; McLaren & Bates, 2012). Even though female cancer patients have limited time to decide on fertility preservation, some have expressed gratitude for assisted reproductive technologies, as the technology provided them with home the future (Inhorn et al., 2017). Fertility preservation has been referred to as "frozen hope" (Quinn et al., 2010, p.175) by some patients; however, this does not come without any consequences and many women still face unpleasant emotional, physical, and psychological distress. In addition, fertility preservation does not guarantee the future parenthood.

1.3 Research Rationale

Infertility due to cancer not only entails physical consequences, but also emotional and psychological consequences, such as feelings of failure, injustice, and symptoms of depression (Perz & Ussher, 2018; Zuraida, 2010). The psychological impact of post-cancer infertility can be enduring (Avila, 2016). Infertility has been commonly associated with negative psychosocial consequences, however existing literature has predominantly captured this information quantitatively (Dyer, Abrahams, Mokoena, Lombard, & van der Spuy, 2005). For example, quantitative studies have found a negative relationship between infertility and life satisfaction (Lopategui, Yechieli, & Ramasamy, 2017), and a positive relationship between infertility and depressive symptoms (Croson & Keim-Malpass, 2016; Perz & Ussher, 2018; Zuraida, 2010).

Research has reported a strong relationship between quality of life and infertility (Armuand & Wettergren, 2014; Obeidat et al., 2014). Patients have reported that preserving their fertility was central to their quality of life after cancer treatment (Deshpande, Braun, & Meyer, 2015; McLaren & Bates, 2012).

Although research has reported on fertility preservation techniques (de Carvalho, Kliemchen, & Woodruff, 2017; Hart, 2008; Malina & Pooley, 2017), perspectives of oncology specialists and patients about fertility preservation (Dancet et al., 2011; Noyes, Knopman, Long, Coletta, & Abu-rustum, 2011; Quinn & Vadaparampil, 2013), and patients' experiences of fertility preservation due to cancer, the research was predominantly conducted in more developed countries. Little is known about subjective experiences of fertility preservation in South Africa, and this provided the rationale for the current study.

1.4 Research Question

The research question for this study was as follows: "what are the subjective experiences of fertility preservation among cancer survivors who received fertility preservation at private infertility clinics in South Africa?

1.5 Aims and Objectives.

The objectives of this study were as follows:

- To understand the factors that played a role in the decision-making process regarding fertility preservation.

- To explore the process of fertility preservation among female cancer survivors in South Africa.
- To explore the emotional aspects of fertility preservation female cancer survivors in South Africa.
- To explore the physical aspects of fertility preservation female cancer survivors in South Africa.
- To explore fertility-related thoughts and concerns among women who received fertility preservation.

1.6 Thesis layout

The present study provided information regarding the subjective experience of fertility preservation. This chapter included the introduction, problem statement, research rationale, research question, aims and objectives for the study.

Chapter 2 will provide the reader with a summary of the literature pertaining to cancer and fertility preservation.

Chapter 3 contains and outline of the theoretical framework that I used in this study as well as my justification for using the theoretical framework.

In Chapter 4, I provide an overview of the methodology employed during this study, including but not limited to the research design, participant selection and recruitment, data collection, data analysis, trustworthiness of the study and ethical considerations.

The findings of the study are presented in chapter 5 and are followed by a discussion of these findings in chapter 6. Finally, chapter 7 contains the conclusion, limitations of this study and recommendation for future research.

1.7 Conclusion

Cancer treatment may result in infertility in patients (Assi et al., 2018; McLaren & Bates, 2012a; Pinelli & Basile, 2018). Fertility preservation may help patients preserve their fertility for after cancer treatment (David & Orwig, 2017; Gardino et al., 2011; Kelvin, 2016). However, very little research has explored the experiences of patients who opted for fertility preservation when diagnosed with cancer (Dahhan et al., 2021; Pedro & Faroa, 2017; Pedro & Mwaba, 2013; Vitale et al., 2018a) and no research about this topic has been reported from South Africa. In this chapter I have outlined the problem statement, research rationale, research question and aims and objectives of this study.

Chapter 2: Literature Review

2.1 Introduction

Current literature on fertility preservation predominantly stems from developed countries with very little research published from South Africa. The local literature is focused on the medical aspects of fertility preservation with no research on the subjective experience of oncology patients. In this chapter I discuss literature on cancer, fertility preservation and onco-fertility. The chapter is organized in five main sections that provide context to subjective experience of fertility preservation among cancer patients. The first section is an overview of findings from previous studies on the psychosocial aspects of living with cancer. This section provides some context in which oncology patients seek fertility preservation treatment. The second section contains information on fertility preservation, with a brief description on various medical techniques and psychosocial aspects of fertility preservation. This is followed by the third section which summarizes the current literature pertaining to psychosocial aspects of onco-fertility. The fourth section provides a description of the barriers associated with seeking or not seeking fertility preservation.

2.2 Psychosocial aspects of living with cancer

Cancer is regarded as a critical, personal, and public health problem globally and in South Africa (Herbst, 2015; Moodley et al., 2016). It is a complex disease that places significant burden not only on the patient, but their loved ones and on health services (Moodley et al., 2016). Psychosocial approaches to illnesses, such as cancer, acknowledge a relationship between the illness and the psychological (e.g., cognitive and emotional) and social (e.g. interpersonal) domains of the patient’s life (Marks, 2018). Existing literature, both qualitative and quantitative, have reported on these psychosocial aspects of being diagnosed and living with a cancer (see Clay, 2013; Duffy & Aquino-Russell, 2007; Guenther et al., 2012; Savio & Priyalatha, 2014; Smith, Osborn, 2007; Warren et al., 2018; Williams & Jeanetta, 2016). This part of the literature review consists of four sub-themes namely, (1) quality of life among cancer patients; (2) coping and fear; (3) psychological well-being among cancer patients, and (4) viewing cancer through the lens of South African females.

2.2.1. Quality of life among cancer patients

Being diagnosed with cancer can be a traumatic experience with significant consequences for the individual diagnosed, impacting several aspects of their life (Hassen et al., 2019a; Williams & Jeanetta, 2016a). Quality of life is an important consideration for patients with cancer. Maintaining and improving quality of life is an important objective for clinicians throughout the patient's treatment trajectory (Abegaz et al., 2018; Coetzee et al., 2019; Hassen et al., 2019a; Raijmakers et al., 2018; Sibeoni et al., 2018). Researchers are also interested in investigation quality of life. This research typically, but not always, involved the use of psychometric measures to measure the quality of life among patients, thereby quantifying quality of life along several domains such as physical functioning, social and sexual functioning, and mental health (Neron et al., 2019; Sibeoni et al., 2018). For example, researchers explored quality of life among 768 Indian cancer patients and concluded that 82% of the sample reported low quality of life, with financial, physical, and emotional domains of quality of life being most affected (Nayak et al., 2017).

Findings similar to this were reported in the study by (Raijmakers et al., 2018) among 458 cancer patients in Netherland. Results from the study indicated that patients reported significantly lower levels of physical functioning, extreme fatigue, and a decrease in their appetite during the last stages of their lives (Raijmakers et al., 2018). Some studies also report on factors that predict quality of life in cancer patients. For example, a study among 150 cancer patients in Ethiopia concluded that metastasis (cancer that has spread) and satisfaction with care predicted quality of life. Treatment options and other factors (e.g., physical, and sexual functioning) may impact the patient's overall emotional, physical and social well-being, therefore compromising the quality of life (Binotto et al., 2020; Dierickx et al., 2018; Hassen et al., 2019a; Nayak et al., 2017).

Numerous studies have revealed that inevitably treatment options such as chemotherapy, radiotherapy and hormonal therapy may have an impact on patients' quality of life (Hassen et al., 2019b; Izycki et al., 2016a; Pandey et al., 2006a; Safaee et al., 2008). Common physical side effects of chemotherapy such as fatigue, pain (muscle, headaches, and stomach pain), nausea and vomiting, nervous system disorders (tingling, shaking, burning sensation, loss of balance) and memory loss (chemo brain) all contributed to a decrease in quality of life (Binotto et al., 2020; Center for Disease Control and Prevention, 2017; Hassen et al., 2019a; Mehnert et al., 2018; Raijmakers et al., 2018). Findings from a quantitative study conducted by (Binotto et al., 2020) sampling 33 Brazilian women revealed that the physical side effects of chemotherapy, such as hair loss and body changes, led to stigmatization according to these women. Pain severity has also been negatively, significantly correlated with quality of life (Angarita et al., 2016; Armuand & Wettergren, 2014; de Carvalho et al., 2017a; Wirtberg et al., 2007).

In conclusion, there is a large body of research indicating that cancer patients experience impairment to the quality of life during their treatment. This section was included to provide some context as to what patients with cancer experience.

2.2.2. Coping and fear

Coping strategies are defined as behavioural and cognitive tactics people use in the face of stress/and or trauma to help manage and adjust painful, overwhelming, or difficult emotions to maintain their emotional well-being (Sharma, 2003). Researchers report that attempting to gain control is used as a coping mechanism in an effort to construct order in a crisis or disruptive situation, such as cancer (Savio & Priyalatha, 2014). One way in which cancer patient may try to cope is by regaining some of their physical independence that may have been lost during cancer treatment (Smith et al., 2019). Similarly, results from a qualitative study with 11 female cancer patients living with ovarian cancer in Texas concluded that despite the complexity of their situation, participants tried to maintain a sense of normalcy by maintaining daily routines and becoming proactive in the hopes of a healthy outcome (e.g., exercising and taking vitamins) (Guenther et al., 2012). Even though the women remained physically active and appeared to be healthy, the women viewed the cancer as “lurking”, with death being a close reality (Guenther et al., 2012). Moreover, the researchers recognized that the expectation of death being a reality, resulted in many of these women prioritizing activities they had always wanted to do (Guenther et al., 2012).

Similar results were revealed in the study conducted in New Zealand by (Miller, 2005) among 10 oncology patients. Women stated that they “live[d] in the moment” (p.22) after their cancer diagnosis. Many of the women focused less on household chores and placed greater emphasis on traveling and spending time with loved ones. Changes in behaviour towards positive activities helped some survivors alleviate anxiety and fear (Miller, 2005). These examples of positive-oriented coping are known as benefit finding, and while this may offer some psychological benefits for patients, there is no evidence that benefit finding improves health outcomes (Pascoe & Edvardsson, 2013).

Although certain behaviours may change, and this change may give a sense of control over maintaining mental well-being (Parton et al., 2019a), fear of cancer reoccurrence is prevalent and may persist long after being diagnosed and treated (Vandraas et al., 2020). Living in constant fear of cancer reoccurring may impact cancer survivors' psychological well-being (Guan Ng et al., 2017; Santre et al., 2014), and can result in intrusive thoughts and avoidant behaviour (i.e., going to the doctor for routine mandatory check-ups) (Fisher & Hammarberg, 2012; Savio & Priyalatha, 2014). Researchers note that the process of normalizing new ways of being after receiving a cancer diagnosis and undergoing treatment is a continuous and complicated process for any patient (Izycki et al., 2016a; Miller, 2005; Warren et al., 2018).

2.2.3. Psychological well-being among cancer patients

Numerous studies during the last few decades have shown that a cancer diagnosis and multimodal treatment are related to an increased risk of emotional distress (mental anguish) and mental disorders (e.g., clinical depression) (Arora et al., 2019; Bard & Sutherland, n.d.; Guenther et al., 2012; Izycki et al., 2016a; Liu et al., 2017; Mehnert et al., 2018; Shankar et al., 2017; Shian Ming et al., 2014). High rates of psychological distress, anxiety, and depression have been found through self-reporting or screening measures (Arora et al., 2019; Chiou et al., 2016; Mehnert et al., 2018; Ng et al., 2017a; Niedzwiedz et al., 2019; Yousif Aly & Mohamed, 2017).

The physical burden and stigma associated with cancer may result in feelings of sadness or anger (Binotto et al., 2020). The psychological impact of cancer has received considerable attention among researchers, as cancer is directly associated with psychological distress (symptoms of anxiety, depression, worry and fear) (Althof et al., 2005; AS, 2010; Hasanpoor-

Azghdy et al., 2014; Pandey et al., 2006a) and quality of life (Armuand & Wettergren, 2014; Kagee et al., 2018; Noyes et al., 2011; Suwankhong & Liamputtong, 2018).

An observational study among 344 cancer patients admitted to a tertiary care facility in India found that at the time of admission, 41.5 % reported moderate to severe pain, 20.3% reported suffering from symptoms of anxiety, and 24.8% reported symptoms of depressive symptoms (Arora et al., 2019). Their study, and several others, indicate a correlation between pain and symptoms of depression and anxiety among oncology patients (Hong & Tian, 2014; Izycki et al., 2016b; Santre et al., 2014).

Similarly, another quantitative study undertaken in Saudi Arabia among 148 cancer patients undergoing radiotherapy reported modest levels of psychological distress (Almigbal et al., 2019). Participants who were married experienced increased vulnerability to psychological distress, depressive symptoms, and symptoms of anxiety due to the pressure put upon the relationship. Furthermore, it was reported that young women who were diagnosed with advanced stages of breast, and ovarian cancer reported increased levels of anxiety due to the perceived morality rate and surgery that goes with these specific types of cancer (Almigbal et al., 2019). Moreover, patients who were younger and had advanced stage cancers demonstrated greater susceptibility to psychological distress (Almigbal et al., 2019).

The finding that age was a significant predictor of psychological distress has been reported in several other studies. These studies report that depression, and symptoms of depression and anxiety were greater among patients below the age of 55 years than above this age (Chiou et al., 2016; Ng et al., 2017b; Niedzwiedz et al., 2019; Zuraida, 2010). In contrast, a study from Germany identified significantly higher levels of anxiety and depression among middle-aged patients (mean age 58) than younger patients (mean age 32) (Mehnert et al., 2018). Despite the different outcomes of the research, age was shown to significantly correlate with psychological distress. This could be related to the obligations that emerge in different life phases such as having children, employment opportunities and reaching other milestones (Almigbal et al., 2019; Chiou et al., 2016)

I only found one quantitative study about psychological distress among cancer patients in South Africa (Kagee, Roomaney, & Knoll, 2018). A total of 201 participants were recruited through convenience sampling at the breast clinic in the Western Cape. Participants from this study were given a questionnaire battery of tests to complete. Results from this study revealed that in total, 34% of the participants reported elevated scores of psychological distresses on the Hopkins Symptom Checklist measurement. Results from regression analysis indicated that the changes in their physical appearance (hair loss, weight, surgery) and perceived social support were significant predicting factors of psychological distress. The effect of cancer may and can cause a variety of psychological distresses for individuals and may cause them to experience psychological distress (Aly et al., 2017; Kagee et al., 2018; Tian & Hong, 2016).

Qualitative research may also provide novel insights the experience of distress among cancer patients. For example, findings from a qualitative study conducted by (Warren et al., 2018) with seven Australian women revealed that participants reported that social support acted as a protective factor against distress, whereas feelings of isolation and alienated were regarded as risk factors that could contribute to distress.

The participants reported that they experienced fear, loneliness, and hopelessness as result of the cancer diagnosis and some reported that they felt disabled by their depressive and anxiety symptoms (Warren et al., 2018). Research has demonstrated that cancer and treatment are already associated with negative psychological outcomes, therefore adding fertility concerns to this creates an additional layer of psychological distress to an already distressing situation (Inhorn et al., 2017).

2.2.4. Viewing cancer through the lens of South African females

The global cancer burden is expected to increase by 50% by 2030, with most of the burden affecting low-and-middle income countries, such as South Africa (Harries et al., 2020). A myriad of factors has been reported on in previous literature that inform how South African women perceive a cancer diagnosis and treatment (Lambert et al., 2020; Mncwabe et al., 2021; Zwane, 2021). Social issues such as disclosure and stigma are examples of some of these factors (De Ver Dye et al., 2011). For instance, in a study by (Nadasen, 2017) social issues and stigma were also found to impact participants' experiences of cancer when it came to disclosing their diagnosis. Participants reported that informing their family about their cancer diagnosis was one of the most difficult and emotional tasks of their cancer experience. Women stated that the arduous task of informing their family was related to their concerns about being treated differently and becoming less valued. Therefore, many of them stated that they felt that they had to put up a façade and appear strong for their families, while dealing with their own mortality concerns to avoid excessive pity, shame, and blame (Nadasen, 2017). Other local studies also indicate that cancer diagnosis can contributed to feelings of shame, guilt, stigma, and internalized stigma (Meacham et al., 2016; Mncwabe et al., 2021; Zwane, 2021).

Mncwabe et al (2021) provide further insights into the local cancer experience. Their study was conducted among 16 South African oncology patients in Kwa-Zulu Natal. Women perceived cancer as a distressing and emotional experience. Many reported feeling isolated or rejected by family and friends but found comfort in a support group. Similarly, (Zwane, 2021) conducted a study in South Africa among 30 Zulu female oncology patients to examine the perceptions of breast cancer patients from underprivileged parts of Kwa Zulu Natal (KZN). They found that in South Africa, especially within African cultures, cancer-free breasts were associated with beauty, while cancer was associated with witchcraft, demons, and magic (Zwane, 2021). Moreover, women from the study reported that they felt as if they were blamed, stigmatized, and shamed by their husbands, families, and community members for their cancer diagnosis. Having some knowledge about cancer and that this disease is treatable and survivable and having adequate support may assist women to overcome perceived or self-stigma and engage with care rather than remaining ashamed of their symptoms and alone with their illness (De Ver Dye et al., 2011; Meacham et al., 2016).

In this section of the literature review I have provided a summary on the impact of cancer on patients. I did this by first reporting on the quality of life of patients, then their experiences of coping and fear in the context of cancer. I then provided information about psychological well-being among cancer patients and concluded this section of the review by reporting on local, psychosocial cancer research. In the next section I describe fertility preservation.

2.3 Fertility preservation

Assisted reproductive technologies offer the best chance of a successful pregnancy after cancer treatment (Letourneau et al., 2011; Tao et al., 2011). Established techniques, such as embryo cryopreservation (embryo freezing) and oocyte cryopreservation (egg freezing) or more experimental techniques, such as ovarian tissue cryopreservation, ovarian transposition are used in assisted reproductive clinics to assist individuals (Dayal, 2012; David & Orwig, 2017; Kim & Jeon, 2012; Noyes et al., 2011). Two of the most common and highly successful techniques currently available are embryo cryopreservation (40% success per transfer; varies by age) and oocyte cryopreservation (reported success rates between 70% and 90%, depending on age at the time of process) (Dayal, 2012).

In the next section I will briefly outline the suitability criteria for fertility preservation among cancer patients and the different assisted reproductive techniques used among individuals who are suitable. This information will become relevant in subsequent chapters when the results and discussion are presented.

2.3.1 Suitability for fertility preservation

Candidates suitable for fertility preservation include women diagnosed with cancer, but who have not commenced any form of cancer treatment (Bedaiwy & Falcone, 2006). Women under the age of forty years are more suited to fertility preservation techniques than women over the age of forty years, as they have a greater chance of achieving pregnancy after cancer treatment (Maltaris et al., 2008). Several fertility preservation techniques are available to female cancer patients (De Vos et al., 2014; Lopategui et al., 2017; Quinn et al., 2010). Some popular fertility preservation techniques include, ovarian tissue freezing and grafting, oocyte cryopreservation, and embryo cryopreservation.

2.3.2 Assisted Reproductive Technologies

Embryo cryopreservation is one of the most widely used options for preserving cancer patients’ fertility with well-defined success rates (60%) being recorded globally (Levine, Canada, & Stern, 2010; McLaren & Bates, 2012; Noyes, Knopman, Long, Coletta, & Abu-rustum, 2011). This method involves using an in vitro fertilization course. This involves ovarian stimulation, oocyte retrieval, fertilization of the oocyte in a laboratory resulting in an embryo, freezing, and storing the embryo (Kim & Jeon, 2012; Levine et al., 2010). This method requires sperm and is only applicable to patients who have a male partner, or those who are willing to use a sperm donor (Kim & Jeon, 2012). This procedure occurs 10-14 days from menses to follicular development and necessitates a delay in chemotherapy treatment (Levine et al., 2010; McLaren & Bates, 2012). One of the major concerns in using this treatment is that this procedure requires the use of a high serum oestrogen concentration during ovarian stimulation and may not be useful for patients with hormone sensitive cancers as it may cause progression of the cancer (Kim & Jeon, 2012; McLaren & Bates, 2012).

Oocyte cryopreservation also referred to as egg freezing is the second most common method of fertility preservation (Levine et al., 2010). This technique involves stimulating the ovaries, harvesting the ovum or eggs, and then freezing them for later use (Levine et al., 2010). Oocyte preservation does not require donor sperm and is therefore ideal for women who either do not have partners or are not ready for pregnancy (Bedaiwy & Falcone, 2006). This technique remains precarious for patients with hormone sensitive cancers due to the ovarian stimulation (Cobo et al., 2008).

Ovarian tissue cryopreservation is an option for female patients who require immediate chemotherapy, as this method does not include any ovarian stimulation nor sperm (Levine et al., 2010). This method involves laparoscopic procedure to harvest a small part of ovarian tissue, and then freezing this tissue for later use (Angarita et al., 2016; Gunasheela & Gunasheela, 2014; McLaren & Bates, 2012). After receiving cancer treatment, and being disease free, the tissue is thawed and re-implanted into the pelvic cavity (Levine et al., 2010). Ovarian tissue cryopreservation is new but promising and less invasive than the other technique and has shown some success (57% live birth rate), however, currently only a few countries such as the United Kingdom offer this technique (Levine et al., 2010; McLaren &

Bates, 2012). The first live birth using this method was recorded in 2004 in Belgium, by 2016 a total of 60 live births were recorded after using this method (Angarita et al., 2016). This technique may pose a risk of cancer recurrence in patients with certain cancer types, such as gastric and endometrial cancers (Levine et al., 2010).

Ovarian transposition is considered another new method in which patients, particularly those who are expected to undergo radiation in their pelvic area, may benefit from (McLaren & Bates, 2012). This laparoscopic method involves moving the ovaries 3cm out of the pelvic irradiation field towards the upper, the exact location is determined by the treatment plan as well as the patient's anatomy (McLaren & Bates, 2012). After receiving treatment, the ovaries are then usually moved back into the pelvic area (Levine et al., 2010).

Although there are various other fertility preservation methods available such as gynaecological surgery (Kim & Jeon, 2012), immature oocyte cryopreservation and in vitro maturation (Lopategui et al., 2017; Salama & Woodruff, 2015), human ovary autotransplantation (Salama & Woodruff, 2015) and whole ovary cryopreservation (Donnez & Ph, 2013; Gunasheela & Gunasheela, 2014), to preserve future fertility, are the most well-known and used techniques.

Becoming a parent is one of the major transitions in adult life among women and men, however this is often taken away from women and men due to cancer treatments. The techniques discussed above are often used to treat infertility, however in the field of onco-fertility, cancer patients explore reproductive options to secure their fertility before undergoing cancer treatment as this may result in infertility. The stress of facing possible infertility due to cancer has been associated with emotional reactions such anger, depression, anxiety, relationship problems, feelings of hopelessness, sadness, and feeling of being worthless (Hasanpoor-Azghdy et al., 2014; Mehnert et al., 2018; Pandey et al., 2006b; Vitale et al., 2018b).

Research has shown that the psychological impact of infertility can be devastating to the person affected as well as their partner (Malina et al., 2016; Sreshthaputra et al., 2008). In the remainder of this chapter, I will discuss the psychological aspects of infertility, such as infertility-related distress among cancer patients, the relationship between infertility and psychosocial well-being of cancer patients, and the effects infertility may have on the couple.

2.4 Psychosocial impact of infertility

In several studies, individuals affected by infertility have expressed a disruption in multiple aspects of their lives (personal, marital, social, physical, emotional, financial, and spiritual), contributing to depression, anxiety, stigma, psychological distress, social isolation, poor sexual health, and low self-esteem (Croson & Keim-Malpass, 2016; Donarelli et al., 2016; Monjelat et al., 2018; Parton et al., 2019b; Pook, 2007; Zuraida, 2010). The following section will focus on the psychosocial impact of infertility, on both the individual and couple. The first sub-section will focus on infertility-related distress among individuals, while the second sub-section will focus on culture and infertility-related distress, and the last section will focus on the effects of infertility-related distress on couples and relationships.

2.4.1 Experiencing infertility-related distress

Infertility-related distress refers to the perceived stressors on an individual’s mental, physical, social networks, and marital relationships in the context of infertility (Boivin & Schmidt, 2005; Logan & Anazodo, 2019). The medical definition of infertility is the inability to fall pregnant despite having regular timed and unprotected intercourse for one year without the use of contraceptives (Born, 2015; Merwe, 2010; Pedro, 2015; Wirtberg et al., 2007).

Biological parenthood has been recognised as a central life goal for many women and men (Letherby, 1999a; McQuillan et al., 2003; Pedro, 2015). Infertility represents a developmental interruption in an individual's expected life course (Taubman-Ben-Ari, 2019). Furthermore, growing research has indicated that infertility has been related to a substantial amount of stress and emotional challenges and has been linked to lasting psychological distress (Dyer & Quinn, 2016; Lakatos et al., 2017). For example, a study of 153 females and 123 males attending a fertility clinic in Hungary, found that 59% of the women and 36% of the men said that infertility was the most upsetting emotional experience of their lives (Cserepes & Bugán, 2015a). Results from a mixed method study conducted among 1 830 Australian women revealed that infertility due to cancer treatment remained a significant source of distress (Parton et al., 2019b). Arguably, despite the fertility related concerns experienced by women, the uptake of fertility preservations remains low. Results indicated that 915 of the 1 830 cancer patients reported that breast cancer had affected their fertility, or that they were uncertain about their fertility status, whereas the other half indicated that they were unable to report changes to fertility as they experienced menopause prior to their cancer diagnosis (Parton et al., 2019b).

Participants associated undergoing fertility preservation and experiencing pre-menopausal symptoms (fatigue, bloating and hot flushes) with negative feelings and changes in their sexual and physical functioning. While several women were able to adjust to the changes, others reported feeling anxious and uncertain about their future fertility status (Perz et al., 2014). Moreover, several participants expressed that they felt angry and confused during their fertility preservation process since they received little to no information about fertility preservation techniques or what they could expect from the process.

Similarly, in a study conducted among 21 married women undergoing fertility treatment in South Africa, (Pedro & Faroa, 2017) provide insight into the lived experiences of fertility treatment and care by South African women with infertility. Participants felt that they were deprived from valuable support and information due to the lack of compassion, support and understanding from their doctors (fertility specialists) (Pedro & Faroa, 2017). While most of the women reported that despite the support and understanding from the nursing personnel, the lack of knowledge and information still existed and were of concern (Pedro & Faroa, 2017). Furthermore, the need for psychosocial (counselling) and financial support were of importance to the women (Pedro & Faroa, 2017). The same study found that infertility was accompanied by psychological and emotional strain, whereby women reported emotional turmoil characterised by disappointment and shock, anger and frustration and a sense of sadness (Pedro, 2015). This research and others demonstrate that while infertility is normally treated medically, the emotional and psychological consequences are undeniable (Bedaiwy & Falcone, 2006; Pedro, 2015; Sheth et al., 2018). These findings were identical to those of previous studies by (Levine et al., 2010; Perz et al., 2014), who found that infertility and premature menopause caused significant distress and anxiety among young cancer patients. Women who were closer to natural menopause reported acceptance of their fertility status, change in sexual functioning, and acceptance of changes in their bodies (Perz et al., 2014).

Individuals affected by infertility tend to score high on anxiety, depression, and grief scales, moderate to high in cognitive tests (e.g., The Montreal Cognitive Assessment), and low on sexual and martial satisfaction (Fisher & Hammarberg, 2012; Hasanpoor et al., 2014; Kowalczyk et al., 2019; Monga et al., 2004). A comparative quantitative study was conducted among 135 infertile and 93 fertile Chinese women to determine the psychological well-being of women with and without a history of infertility (Lakatos et al., 2017). Researchers found that infertile women were younger (age 33.30 vs. 35.74, $p = .001$), reported significantly worse psychological well-being (BDI = 14.94 ± 12.90 vs. 8.95 ± 10.49, $p < .0001$) compared to their fertile counterparts (Lakatos et al., 2017).

Similarly, a quantitative study assessed psychological distress among 120 women suffering from infertility in an urban community in South Africa using the Centre for Epidemiological Studies Depression scale (CES-D) (Dyer et al., 2005). Women diagnosed with infertility reported a significant amount of stress, however, contributing factors such as age, culture, emotional well-being, and financial status were associated with infertility-related distress (Dyer et al., 2005). While infertility is not a disease, infertility-related distress can lead to several psychological, emotional, marital, and financial concerns (Donarelli et al., 2016; Lakatos et al., 2017; Ussher & Perz, 2019). In the context of sexual-health, the effects of infertility and infertility-related distress has been widely documented among the literature (Duthie et al., 2017; Obeidat et al., 2014).

2.4.2 Culture and Infertility

Culture has been identified as a contributing factor in the experience of infertility-related distress due to the pressure women may feel to bear a child (Makoba, 2005b). For example, Batool and de Visser (2016a) demonstrated the cultural influences and experiences are present in the context of infertility-related distress in a cross-cultural qualitative study among eight women living in the United Kingdom (UK) and eight living in Pakistan. Results from the semi-structured interviews revealed that both infertile women in the UK and Pakistan had many common experiences such as the desire for motherhood, however, these women faced unique psychosocial challenges due to their environmental and cultural contexts (Batool & de Visser, 2016). Women from both countries showed signs of anxiety, depression, low energy, low mood, sleep disturbance, sense of failure, and loss of confidence (Batool & de Visser, 2016). In addition to this, women in Pakistan revealed experiencing more pressure from family members, partners, and society than women in the UK, which contributed to increased anxiety, stress, and depression for them (Batool & de Visser, 2016). Moreover, clear differences existed between the sample, women from Pakistan expressed experiencing increased societal-related distress in terms of judgement, guilt, and influence from their family and friends., which the UK participants did not report (Batool & de Visser, 2016).

Both infertility and fertility treatment are a source for both psychological and emotional distress among women (Duffy & Aquino-Russell, 2007; Dyer et al., 2005; Hasanpoor et al., 2014). Results from a qualitative study among 25 Iranian women, between ages 21- and 48-years seeking fertility treatment, revealed that they viewed infertility as a life crisis with psychological and emotional challenges (Hasanpoor et al., 2014).

According to (Hasanpoor et al., 2014) women revealed that having an external locus of control created a significant amount of stress relating to possible infertility. A total of 12 participants reported a decrease in their self-esteem and a sense of failure because required medical reproductive assistance to have a child (Hasanpoor et al., 2014). Intrusive thoughts about cancer treatments included fear, anxiety and worry, fatigue and helplessness, grief and depression, and hopelessness. Both (Makoba, 2005a; Naab & Kwashie, 2018) suggest that traditional influences are the primary role in infertility related distress, stigmatization, blame and emotional disturbances. For example, (Naab & Kwashie, 2018) explored the concerns of 12 infertile men in Ghana about their infertility and the blame falling on their wives.

Researchers found that traditional influences such as cultural beliefs and practices were identified as a primary factor for blame shifting, emotional disturbances and placing pressure on their wives to seek medical treatment.

In traditional African cultures it is believed that infertility is a female problem (Naab & Kwashie, 2018). Furthermore, men reported that their emotional reactions to infertility included sadness, worry, and fear, while dealing with concern about their wives' mental well-being (Naab & Kwashie, 2018). Interestingly, (Makoba, 2005b) reported that most of the time women are generally pressured to seek professional assistance first when dealing with infertility, and only once their wives are deemed fertile, are men assessed. Therefore, due to the cultural component of infertility, women in countries such as Ghana and South Africa frequently carry the burden of infertility and find themselves having to navigate a cancer diagnosis, body changes, stigmatization, and infertility (Izycki et al., 2016a; Letherby, 1999b; Monga et al., 2004; Williams & Jeanetta, 2016b). Similarly, (Mabasa, 2005) found in her study among 76 infertile South Africans, that couples were pressured to reproduce as soon as they got married, if the couples were not able to reproduce, blame was publicly shifted onto the women, while men's inability to reproduce was kept a secret among community members. Moreover, the study also found that social support and stigma was modulated by the community's perception of infertility and the causes thereof, such as adultery, witchcraft, or a consequence of abortion (Mabasa, 2005). Similarly, (Dyer et al., 2004) reported in their study among 27 South African couples experiencing infertility, communities retracted support, stigmatized, verbally abused, and revoked infertile individuals' social status when they were made aware of their infertility.

Cultural difference appears to be a major contributor to psychological burden, sexual and relational concerns (Cserepes & Bugán, 2015b; Naab & Kwashie, 2018). For example, a comparative study conducted by (Cserepes & Bugán, 2015) among 270 German and Hungarian couples, concluded that Hungarian couples experienced significantly higher levels of anxiety and depression than German couples. Furthermore, as sexuality is an important component of self-esteem and a couple's relationship, couples from both cultural groups reported having sexual and relational concerns (Cserepes & Bugán, 2015b). Moreover, the author concluded that female depression and anxiety was a significant contributing factor correlating with the couple's sexual satisfaction and quality of life. In a study conducted in Pakistan, (Mumtaz et al., 2013) explored the experience of infertility among 12 women and eight men. Women reported abuse (physical and emotional) and stigmatization directed towards the couple, while men only experienced minor taunting from friends (Mumtaz et al., 2013), indicating that responses to infertility are gendered. Moreover, women reported that the consequences of the couples' infertility caused a significant decrease in their quality of life, affecting all aspects of their lives, including marital and sexual satisfaction (Mumtaz et al., 2013).

2.4.3 Effect of infertility on couples.

Experiencing cancer and infertility can lead to infertility-related distress, which can affect romantic relationships (McLaren & Bates, 2012b; McQuillan et al., 2003). Infertility as a joint experience could strengthen the relationship but could also generate conflict between the members of the relationship (Mai, 2008). As with individuals, relationships facing infertility may experience a range of negative feelings such as shock, guilt, anger, denial, grief, and isolation (Malina & Pooley, 2017; Obeidat et al., 2014; Tao, Coates, & Maycock, 2011).

While women bear the brunt of infertility treatment, studies show that men and women seeking fertility treatment experience similar levels of infertility related distress (Cserepes & Bugán, 2015b; Sreshthaputra et al., 2008). For example, a study conducted in Thailand among 111 couples concluded that although individuals of both genders experienced high levels of stress, no difference in gender and infertility-related distress was reported (Mai, 2008). Male and female infertility patients experienced similar levels of infertility-related distress, sexual and relational concerns, and their need for parenthood (Mai, 2008).

In a quantitative study conducted in Portugal among 139 couples' seeking fertility, and subsequently discontinuing fertility treatment, (Pedro et al., 2017) found five significant predictors of couples' discontinuation of fertility treatment. Using the couple as unit of analysis researchers reported that female age, education level, type of assisted reproductive techniques, female causation for the fertility difficulties and female depression predicted the decision to discontinue fertility treatment (Pedro et al., 2017). Moreover, female depression was found to be the strongest predictor in discontinuation of treatment. Although, infertility and fertility treatment were burdensome for men, men tended to suppress their emotions and support their wives (Pedro et al., 2017).

Similarly, in a quantitative study conducted among 61 Polish couples, (Nagórska et al., 2019) reported that both men and women responded to infertility with negative emotions such as intense sadness and anxiety. Furthermore, the researchers concluded that women attempted to talk openly about their infertility and accept fertility treatment, while their male partners were more restrained and inclined to decline fertility treatment (Nagórska et al., 2019). As (Hawkey et al., 2021) suggest in their study conducted in Australia among 144 partners, couple communication is central in coping with cancer, as well as coping with the distress associated with infertility. Researchers found that open and honest communication around fertility-related concerns were associated with feelings of understanding, support and strengthened the relationships, whereas hostility and avoidance was associated with relationship breakdowns. Cancer related infertility is known have an impact on the psychological, physical, and sexual health of the infertile couple, causing anxiety and depression (Nagórska et al., 2019; Pedro & Andipatin, 2014; Pedro et al., 2017) and sexual and relational concerns (Hawkey et al., 2021; Monga et al., 2004).

2.4.4 Motherhood and infertility

Research indicates that infertility is associated with psychological turmoil resulting in psychological distress such as symptoms of depression, anxiety, and emotions such as anger (Hasanpoor-Azghdy et al., 2014; Pedro, 2015; Perz & Ussher, 2018). However, many women have indicated fertility-related distress may also stem from the importance placed on becoming a mother. Furthermore, motherhood is an important personal, social, and martial (sic) life goal (Boz et al., 2018) for many women. According to Pedro (2015), Avila (2016) and, McQuillan and colleagues (2008) a variety of complex, multidimensional, and intersecting reasons exists for women wanting their own biological child. These include their own personal morals and values, social, personal, and cultural expectations.

Drawing from the study by (Mumtaz et al., 2013) in Pakistan, women reported that motherhood was a critical milestone after marriage as motherhood was regarded as a source of status and power, and an avenue to ensure marital security. Childbearing, preferably within the first five years after marriage, is considered essential in particular traditions to prove a woman’s fertility, securing a family heir as well as managing familial and societal relations (Cserepes & Bugán, 2015c; Makoba, 2005b; Mumtaz et al., 2013). A quantitative study conducted by (Larsen & Hollos, 2012) in a small rural community in Moshi Tanzania concluded that women who were infertile were stigmatized and called a “moopa”, a term used for women who are barren/sterile (p.29). Furthermore, the researchers stated that in African cultures such as the Swahili culture within the regions of Northern Tanzania where this study was conducted, women who were infertile were excluded from important cultural activities and seen as not valuable (Larsen & Hollos, 2012).

The centrality of motherhood to identity is evident in some qualitative studies. In a study conducted in Jordan, (Obeidat et al., 2014), explored the lived experience of infertility and failed assistive reproductive technologies. A total of 30 women participated in semi-structured interviews. Women reported that their greatest disappointment was missing out on motherhood. Moreover, their dreams of having children and their agony of not being able to have children easily “like other women” was identified as a source of psychological distress (Obeidat et al., 2014).

For some, motherhood is considered a natural instinct and normative, while not having children is considered deviating from the norm (Maher & Saugeres, 2007). Results from a qualitative study among 19 infertile women living in New Zealand concluded that motherhood was seen as natural and biologically imperative (Ulrich & Weatherall, 2000a). Furthermore, childbearing was an important developmental goal in the relationship, and a social expectation once they were in committed relationships (Ulrich & Weatherall, 2000b). Consistent with previous research, infertility represented inadequacy and failure that is reinforced by feelings of shame, guilt, and hopelessness (Ulrich & Weatherall, 2000b).

Literature has shown that women often develop dysfunctional beliefs about themselves in the context of motherhood and identity (Letherby, 1999c). According to (Gentzler, 2011) individuals become highly committed to identities they value, such as motherhood, and therefore the loss of a valued identity has an impact on the psychological well-being. In a qualitative study conducted in Iran, (Alamin et al., 2020) explored the challenges of identity crisis of infertility among 40 women who attended a fertility clinic in the hopes of securing motherhood. The researchers concluded that infertility interfered with the “identity building” of men and women because parenthood was a major contributing factor in constructing their identity (Alamin et al., 2020).

However, it must be acknowledged that motherhood is not a goal for many women and that women who voluntary decide not to have children, often must justify this decision to others (Malacrida & Boulton, 2012). (Maher, 2014) in her study of women’s perceptions on the discourses of motherhood and cultural expectations identified that even though women felt that not wanting children was part of their early identity formation and not of conscious choice, they nevertheless felt the need to understand and rationalize why they did not want children. Women reported that the lack of a stable long-lasting relationship, reluctance to change their lifestyle, fear around motherhood, viewing motherhood as all-encompassing, making it impossible to achieve other important life goals contributed to their decisions to remain childless (Maher, 2014). Some women reported feeling liberated by this choice and were relieved at not having additional responsibilities for others and could pursue their career goals (Peterson, 2015). In a poignant example, (Hershberger et al., 2016) found that young women diagnosed with cancer declined fertility preservation due to the financial and health risks involved, their desire to survive cancer, lack of desire for future children, indicating that not all patients diagnosed with cancer will take up the offer of fertility preservation.

The meaning of marriage, self-worth and self and sexual identity is usually confirmed through parenting, therefore failure to achieve this may lead to major setback in identity building (Alamin et al., 2020). For example, according to (Letherby, 1999a) 24 women from the UK reported that a diagnosis of cancer and facing infertility involved undergoing a change in their identity. Losing fertility may be a radical, life-changing event and result in a permanent scar that causes a barrier to future happiness (Inhorn, Patrizio, Inhorn, & Patrizio, 2015) and prohibits the vision women have of themselves as women and mothers (Ulrich & Weatherall, 2000b). However, the emerging field of onco-fertility, an intersection of cancer and (in)fertility, provides cancer patients with the ability to achieve pregnancy after undergoing treatment by undertaking fertility preservation prior to cancer treatment (de Carvalho, Kliemchen, & Woodruff, 2017a; Gardino, Rodriguez, & Campo-Engelstein, 2011; McLaren & Bates, 2012; Moravek et al., 2018).

2.5 The subjective experiences of Onco-fertility

The term ‘onco-fertility’ was first coined by Dr T.K. Woodruff at the Onco-fertility Consortium in 2006. Onco-fertility research thus far has aimed to explore and expand on options for the reproductive future of cancer patients (Woodruff, 2015). Nonetheless, little research has explored/investigated the psychosocial concerns pertaining fertility preservation on cancer patients (Gowda, Thippeswamy, & Chaturvedi, 2018). This has led to an emerging research field whereby researchers have endeavoured to document the psychosocial effects of fertility preservation techniques on oncology patients (Zomerlei et al., 2018; Brison, 2002; Izycki et al., 2016; Mulder et al., 2016; Quinn & Vadaparampil, 2013). While positive aspects of fertility preservation have been recorded such as providing hope, opportunity, and gratitude for a biological reproduction (Hammarberg, 2001; Melo et al., 2018; Parton et al., 2019a), several have reported the negative impact such as the physical, emotional and social demands (Inhorn & Patrizio, 2015; McLaren & Bates, 2012a; Paton, 2015; Wirtberg et al., 2007).

2.5.1 Physical demands of fertility preservation on oncology patients

Fertility sparing techniques can be both emotionally and physically demanding (Jones et al., 2017a; Turner et al., 2013). Researchers have provided evidence of the physical strain women go through when opting for fertility preservation (Hammarberg, Astbury, & Baker, 2001; Turner et al., 2013), including daily hormone therapy injections, regular blood tests and vaginal examinations (Hammarberg, 2006). A quantitative study conducted in a fertility clinic in the UK among 116 women, 2-3 years after completing fertility treatment, investigated the experience of fertility treatment (Hammarberg et al., 2001). Results revealed that more than half (52%) of the women who completed fertility treatment reported that performing the required daily hormone injections, undergoing oocyte retrieval, and subsequently re-transplanting the embryo/thawed oocyte back into the uterus was a physically demanding process, coupled with stress, anxiety, and fatigue (Hammarberg, 2001). Nearly half (48%) of the participants who did not complete their hormone treatment reported that the physical demands of hormone therapy and oocyte harvesting (such as blood tests, hormone injections, vaginal examinations, and medication) were the reason for terminating their fertility preservation (Hammarberg et al., 2001). Women who had achieved pregnancy, despite the physical demands of the process, reported significantly higher levels of life and marital satisfaction compared to those who did not complete the process (Hammarberg, 2001).

Removing mature eggs after approximately two weeks of hormonal treatment requires surgery and anaesthesia and entails the insertion of a needle through the wall of the vagina and into the ovary (Shalev & Werner-Felmayer, 2012). A study conducted in Germany among 1 058 female patients who had recently undergone hormone treatment and oocyte retrieval found that a total of 135 (12.8%) women reported experiencing vaginal bleeding while five women reported having a ureteral lesion (Ludwig et al., 2006). Furthermore, most participants reported tolerating the procedure relatively well, however, 71 (6.8%) experienced moderates to severe pain and required hospitalization after the procedure (Ludwig et al., 2006).

The surgical risks of egg harvesting for fertility preservation include extensive bleeding, infection in the pelvis, permanent damage to the fallopian tubes, bowel damage, and bruising around the pelvic area (Ludwig et al., 2006; Shalev & Werner-Felmayer, 2012). Research has shown that women who decide to opt for fertility preservation prior to their cancer treatment are likely to find the hormone therapy and gametes harvesting physically demanding and dangerous (Jones et al., 2020; Kimati et al., 2016).

2.5.2 Psychological impact of fertility preservation

The inherent ups and downs of the entire process often leaves patients feeling emotionally overwhelmed with alternating feelings of happiness, sadness, anger, and disappointment (Inhorn et al., 2017). According to (Hershberger et al., 2017) in a study conducted in Chicago among 26 recently diagnosed cancer patients, women of reproductive age felt that their cancer brought upon them a “double jeopardy” of fertility loss and facing potential death (p.5). The double threat was coupled with feelings of anxiety, fear, sadness, hopelessness and anger, however, women who were offered and undertook fertility preservation viewed it as a source of “double hope” (Hershberger et al., 2017). For the women, the life affirming optimism of recovery and survival, along with the imagined future of biological motherhood, alleviated certain negative thoughts (Hershberger et al., 2017).

A medical anthropological study among 45 women with cancer in the United States of America (USA) and Israel examined participants experiences of fertility preservation. All participants had completed at least one cycle of oocyte cryopreservation (Inhorn et al., 2017). For all the women, a cancer diagnosis was unexpected, creating feelings of shock, disbelief, and confusion (Inhorn et al., 2017). Women reported feeling devastated and overwhelmed when they received their diagnosis and were made aware of the potential loss of fertility due to cancer treatment, causing some anticipatory grief in the loss of motherhood (Inhorn et al., 2017). Prompt and direct referrals from healthcare professionals meant that participants could undertake fertility preservation prior to cancer treatment. Participants expressed feeling empowered, blessed, and fortunate to have their gametes preserved (Inhorn et al., 2017).

Although fertility preservation was described as bringing hope to participants, many were uncertain of the future. As noted in previous studies (de Carvalho et al., 2017b; Jeunette, 2016), women who were diagnosed with severe and aggressive forms of cancer frequently faced ethical dilemmas about their frozen gametes and what would happen with these if they were to die (Inhorn et al., 2017). Nonetheless, fertility preservation provided cancer patients the hope for future childbearing, which may increase their motivation to contest their cancer and adhere to treatment (Hoeg, Schmidt, & Kt, 2015; Quinn et al., 2010).

A pilot study in Denmark was conducted among five women under the age of 40 years old, who were diagnosed with cancer and underwent fertility counselling before initiating cancer treatment (Hoeg et al., 2015). The participants stated that fertility counselling and preservation contributed to a life after cancer, in which they found hope that they could survive the cancer (Hoeg et al., 2015). Further results indicated that the possibility of fertility preservation removed a huge concern about their fertility (Hoeg et al., 2015). Women reported that undergoing fertility preservation prior to undergoing cancer treatment provided them with a sense of security, whereby they could focus exclusively on their treatment and recovery (Hoeg et al., 2015). Fertility preservation for oncology patients may be a positive strategy that provides women with a sense of security, control, and relief (Assi et al., 2017; Hershberger, Sipsma, Finnegan, & Hirshfeld-Cytron, 2016).

2.5.3 Hindering and facilitating factors underpinning the decision-making process.

Existing literature has continuously demonstrated the positive and motivational effects of fertility preservation on the psychological well-being of cancer patients (Batool & de Visser, 2016a; Parton et al., 2019a; Tinoco et al., 2013). Despite this optimistic perspective, the lack of support from loved ones and healthcare providers creates a barrier to fertility preservation seeking behaviour (Panagiotopoulou, Ghuman, Sandher, Herbert, & Stewart, 2018; Perz et al., 2014). For example, a qualitative study conducted in Switzerland among 12 women who participated in focus groups examined the needs of young cancer patients regarding the fertility preservation decision-making process (Ehrbar et al., 2016). Participants stated that they would have found the decision-making process easier if they had; 1) more information about fertility preservation after being diagnosed, 2) a consultation with an experienced fertility specialist and 3) written information that they could take home and go through (some of them had forgotten everything as they felt overwhelmed with emotions) (Ehrbar et al., 2016).

(Melo et al., 2018) reported similar findings from their study among 71 recently diagnosed women living in Portugal, whereby a positive fertility preservation decision-making process was informed and promoted by healthcare practitioners. The support provided by oncologist to pursue fertility preservation was associated with higher-quality decision and decisional satisfaction. In contrast, the lack of support from healthcare providers was met with higher levels of decisional regret and lower-quality decisions (Melo et al., 2018).

The decision-making process is complex, and women often fail to uptake fertility treatment at a very crucial time. For many patients, the decision-making process relies on certainties they have, such as the desire for motherhood (Batool & de Visser, 2016; Hershberger et al., 2016; Letourneau, Melisko, Cedars, & Rosen, 2011), and uncertainties that may exist, such as lack of information (Komatsu et al., 2018; Yagasaki & Yamauchi, 2018), and financial constraints (Angarita et al., 2016; Dyer & Quinn, 2016; Quinn et al., 2011). A qualitative study conducted in Japan among 11 women (aged between 33 and 46 years old) explored how women with breast cancer made fertility related decisions (Komatsu et al., 2018a). Participants reported that when confronted with the decision whether to undergo fertility preservation or not, they relied on factors that were explicit (need for motherhood) and factors that they weren’t certain about (cost involved). Several key influential factors with regards to the decision-making process among uncertainty and certainty domains were outlined (Komatsu et al., 2018a). Time constraints, risk of cancer reoccurrence, labelling as a cancer patient, and unmet needs from healthcare providers were all factors which created some uncertainty about undergoing fertility preservation (Komatsu et al., 2018a). Furthermore, emotional support and information regarding fertility preservation were two factors that provided some sense of certainty (Komatsu et al., 2018a).

Notably, cancer patients must manage various uncertainties regarding their fertility and their cancer. However, as (Parton et al., 2019b) noted in their study among 693 Australian cancer patients, patients maintained a positive attitude towards fertility preservation despite the lack of support and knowledge. Researchers conducted a systematic review that explored factors that hindered the decision-making process for female cancer patients who were in the process of considering fertility preservation (Jones et al., 2017). The following factors were reported as hindering the decision-making process, 1) lack of information and limited time to discuss all the information, 2) perceived risks associated with perusing fertility preservation (delaying cancer treatment, aggravating hormone sensitive cancers), 3) personal situation at the time (relationship status, and age), and lastly, 4) financial status (Jones et al., 2017). In addition, individuals reported similar findings in the study conducted by (Ehrbar et al., 2016), where participants reported that lack of support from healthcare workers hindered their decision-making process.

Similarly, in another review of 37 journal articles, Panagiotopoulou and colleagues (2018) identified the barriers and facilitators associated with the decision-making process of fertility preservation in the context of cancer. Results indicated that factors affecting the decision-making process can be categorized as intrinsic or extrinsic (Panagiotopoulou et al., 2018). Intrinsic factors include fertility preservation information, personal values associated with reproductive technologies, clinicians’ attitudes towards fertility preservation, emotional burden, relationship status and age (Panagiotopoulou et al., 2018). Extrinsic factors include available healthcare services, fertility preservation costs and options, and personal support systems (Panagiotopoulou et al., 2018). Individuals with cancer face the ultimate burden of choosing treatment that can be both lifesaving and life threatening (Gracia & Woodruff, 2012; Matthews et al., 2012). Women face several intrinsic and extrinsic factors that influence an irreversible decision about fertility preservation treatment (Jones et al., 2017b; Panagiotopoulou et al., 2018). According to (Ulrich & Weatherall, 2000c) younger patients suffering from primary infertility have recorded experiencing mental exhaustion as result of the complexity of the decision-making process. In a qualitative study among 27 patients, researchers attempted to understand young female cancer patients' reasons for accepting or declining fertility preservation before commencing cancer treatment (Hershberger et al., 2016). Reasons for declining or accepting fertility preservation are related to four theoretical dimensions; cognitive appraisals, emotional responses, moral judgement, and decision partners (Hershberger et al., 2016). Women who declined fertility preservation described more reasons in the cognitive appraisal dimension than other dimensions. This included, but are not limited to, financial costs and potential risks involved in undergoing fertility preservation (Hershberger et al., 2016). Most women who decided to opt for fertility preservation reported a strong desire for biological motherhood and hoped for a life after treatment, whereas women who did not accept fertility preservation reported a stronger desire for surviving their cancer (Hershberger et al., 2016). In the moral judgement factor, three participants explained that fertility preservation raised ethical, moral, and religious concerns for them consequently they declined fertility preservation (Hershberger et al., 2016). Participants described that support from their loved ones, communities and clinicians played a significant role within their decision-making process (Hershberger et al., 2017).

2.6 Summary

It is evident in the literature review above, that a cancer diagnosis may cause severe short and long-term physical, emotional, social, and sexual turmoil for female patients, that affects not just the individual but their romantic relationships. Being diagnosed with cancer has shown to negatively impact individuals' quality of life. Due to the impact a cancer diagnosis may have on the individual, individuals often make use of coping strategies to cope with the fear, change and distress as a means of maintain their psychological well-being. Fertility preservation offers patients that are deemed suitable the opportunity to preserve their gametes for later use through using one of the established fertility preservation techniques.

While a cancer diagnosis may pose physical, emotional, and social challenges, recent scientific advances have contributed to increased survival rates among oncology patients, however, treatment regimens potential leave young, reproductive aged oncology patients infertile. It is evident that infertility related distress may cause psychological turmoil for individuals, their partners, and family members. Culture has been known as a contributing factor in South African women's experience in the context of infertility-related distress due to the social and cultural expectation placed on women by spousal partners, community members and society to reproduce. While women ultimately bear the brunt of couple infertility, researchers have reported that couples too suffer from infertility related distress, which effect the physical, emotional, and sexual relationship.

Biological motherhood has been identified as an important life goal for many women, which supported their main reason for delaying cancer treatment to accommodate fertility preservation. However, several researchers have alluded to the fact that for some women motherhood may not be a life goal, many declined fertility preservation due to the financial and health risks involved, their desire to survive cancer, lack of desire for future children. Based on their goal, in this case, biological motherhood, the subjective experience of onco-fertility illustrated that fertility preservation provided a glimmer of hope and control for cancer patients. Oncology patients reported the option of fertility preservation was a blessing, despite the negative and uncertain consequences of the process, such as the physical demands of the hormone therapy and financial burden. It is evident that personal values, information around fertility preservation, costs and timing, and perceived support were important factors individuals took into consideration when deciding on fertility preservation.

As demonstrated in the literature overview, a cancer diagnosis and subsequently undergoing fertility preservation is a process that is both challenging and demanding on many levels. The process of cancer and fertility preservation is associated with a variety of psychological factors (emotional, physical, and social) that needs to be taken into consideration by oncologist, fertility specialist and more importantly the cancer patient. The proposed study could aid in the identification and understanding of fertility preservation in the local context. The structured review highlighted the gap within the literature on the subjective experience, particularly within South Africa. Moreover, during the research process it became evident that the literature on infertility is largely heteronormative, imply that all couples suffering from infertility are heteronormative. This is not the case and efforts should be made to reflect this.

2.7 Conclusion

This chapter began with a brief discussion on the psychological aspects of living with cancer which included four sub-sections, 1) quality of life among cancer patients, 2) coping and fear in the context of cancer, 3) psychological well-being among cancer patients, and 4) viewing cancer through the lens of South African females. Subsequently, a section on fertility preservation was included, this section was divided into two sections, a brief discussion was included on patient suitability for fertility preservation as well as a brief description of the assisted reproductive technologies currently available to patients. Next, a section on the psychosocial impact of infertility, with four sub-sections were included. The sub-sections were as follow, 1) experiencing infertility related distress, 2) culture and infertility, 3) effects of infertility on couples, and lastly, 4) motherhood and infertility. The last section, the subjective experience of oncofertility included three sub-sections, 1) physical demands of fertility preservation on oncology patients, 2) psychological impact of fertility preservation in the context of cancer patients, and 3) hindering and facilitating factors underpinning the decision-making process. The following chapter provided a discussion on the theoretical framework used in this study.

Chapter 3: Theoretical framework

In this chapter I outline the theoretical framework that I applied in this study. I outline this framework, describe its development, and current application. I also indicate why I chose this framework and conclude this chapter with a critique of the framework.

Developed in the 1950's by psychologists Godfrey Hochbaum, Irwin Rosenstock and Stephen Regels, the health belief model became one of the first health-promoting models, focusing predominantly on individuals' attitudes and beliefs towards health-seeking behaviour (Abraham & Sheeran, 2014a; Janz & Becker, 1984; Tarkang & Zotor, 2015). According to (Jones et al., 2016) the model is constructed under six principal beliefs, namely perceived susceptibility, anticipated severity, benefits or efficacy of a recommended health behaviour, perceived barriers, cues to action and self-efficacy.

According to (Washburn, 2014), perceived susceptibility (frequently referred to as perceived threat) refers to the belief a person may feel that they are susceptible or prone to a health problem or condition. Individuals who feel/believe that they are at risk will occupy themselves in behaviours that prevent or minimizes that risk. Perceived severity is a verbal or cognitive assessment by the individual on the seriousness of the health-related problem or disease (Abraham & Sheeran, 2014b). Washburn (2014) noted that perceived severity can be based on medical consequences of the disease, for example, death or disability or personal beliefs about how the health-condition or disease would affect their lives in the future. When perceived susceptibility and severity are heightened, individuals are more likely to take or seek health-promoting action or change their behaviour in an attempt to avoid a condition or illness (Abraham & Sheeran, 2014c).

Although the health belief model relies on all six factors that contribute to health-seeking behaviour or change, perceived benefits of an action taken is considered one of the most significant factors within the model (Janz & Becker, 1984). According to (Washburn, 2014) perceived benefits refer to the perception the individual places on the value and effectiveness of a certain action in an attempt to minimize or alleviate a condition. Therefore, an individual will undertake a course of action to minimize or remove the perceived threat if they are under the impression that recommended health action was perceived as beneficial and provided positive outcomes. However, (Abraham & Sheeran, 2014b) stated that although a person may perceive a condition as a threat with high levels of severity/risk, and a course of action will provide a beneficial outcome, perceived barriers frequently prevent individuals from engaging in health-seeking/promoting behavioural changes.

Perceived barriers refer to obstacles that prevent individuals from undertaking a course of action to reduce their susceptibility to a certain condition or illness (Guidry et al., 2019). Barriers can be tangible, such as the lack of financial resources, time, knowledge and support, or intangible, such as fear, pain, and embarrassment (Washburn, 2014). Cues to action are considered triggers or cues that initiates the decision-making process to accept a recommended health action or initiate change. These cues could be internal (symptoms associated with the illness) or external (information, advice, and motivation/support) (Abraham & Sheeran, 2014b). Finally, the last construct focuses on the extent to which the individual has confidence in themselves and their ability to successfully perform a course of action (Washburn, 2014).

The health belief model can be applied to fertility preservation as fertility preservation can be regarded as health-seeking behaviour. In this case, according to the health belief model, women’s intention to undergo fertility preservation depend on the perceived barriers and benefits of doing it (Abraham & Sheeran, 2014a; Sharifikia et al., 2019), their perceived susceptibility to infertility and how severe they evaluate the consequences of infertility to be (Gameiro et al., 2019; Sousa-Leite et al., 2019). Moreover, (Ter Keurst et al., 2016) believe that specific cues to action, such as family, friends, healthcare providers, and knowledge may prompt women to consider fertility preservation. (Fulford et al., 2013) stated that the health belief model can predict that fertility knowledge, perceived susceptibility, and severity to infertility risk status, relate to women’s intentions to optimise their future fertility. Using the health belief model to determine the relationship between the six key constructs of the model and fertility care during cancer, (Gorman et al., 2020) found that women who perceived that infertility would incur significant emotional distress were more likely to undertake fertility care. Furthermore, cues to action from family and friends, as well as health care providers were associated with higher fertility care uptake. Despite the severity and susceptibility reported, major obstacles prevent survivors from accessing fertility care prior and post cancer, particularly financial and access barriers (Gorman et al., 2020).

Although the health belief model has had remarkable success in predicting health seeking behaviour such as women’s intentions to undertake fertility preservation (Gameiro et al., 2019; Sousa-Leite et al., 2019; Ter Keurst et al., 2016), it fails to capture a few components that relate to intention to undergo fertility preservation (Gameiro et al., 2019). Firstly, the model does not explicitly spell out the relationship between the constructs and no clear guidelines have been set out for combining and linking the constructs into each other (Washburn, 2014). However, (Rosemann & Brüning, 2014), this weakness or limitation can also be viewed as a strength, due to the lack of strict guidelines or rules, the health belief model offers flexibility that makes the health belief model adaptable and applicable to many health behaviour, different population groups and phenomena. The second major weakness of the health belief model is its predictive capability (Hall, 2012).

For example, results from quantitative reviews of the health belief model suggest that the primary variables (susceptibility, severity, benefits, and barriers) were significant of health-related behaviour in most cases, however, the effect sizes are usually small (Gameiro et al., 2019; Sousa-Leite et al., 2019). This suggest that there are other important variables that determine health seeking behaviour that have not been accounted for by the health belief model. (King et al., 2016) reported that this model does not account for social norms (i.e., social expectation on women to engage in biological motherhood) as well as interpersonal factors (i.e., communication with partner, importance of motherhood). Thus, many researchers (Conner & Norman, 2006; Hall, 2012; King et al., 2016; Taylor et al., 2006) believe that the model is incomplete due to the lack of guidelines and predictive and unaccounted for constructs, despite its high adoption and use by health seeking behaviour promotion researchers. However, (Gorman et al., 2020; Sousa-Leite et al., 2019; Ter Keurst et al., 2016) believed that the health belief model provides a useful framework for investigating health seeking behaviour, such as fertility preservation. In general, all the model's components are seen as independent and appropriate predictors of health seeking behaviour.

In addition, the health belief model has been applied in qualitative research as well as research into infertility and oncology, thus supporting my decision to use the model to frame the current study. I conducted a search for the "health belief model" in the journal Qualitative health research and found 39 articles that referenced the model, indicating that the model was appropriate for a qualitative study. I also conducted a search for the model and "infertility" and found 274 studies using the model. A search for the model and “cancer” generated 2 006 publications and a search for the model and "oncology" found 17 articles, indicating that the model is widely used in cancer research. Altogether, I believe that the findings of these searches indicate the appropriateness of the health belief model in the current study.

Chapter 4: Methodology

4.1 Introduction

Chapter 4 describes the research method used in this study. I start by once again stating the aims and objectives of the study. I then describe the research approach, participant selection and recruitment, data collection, and data analysis used in this study. Thereafter, I include a section on the trustworthiness and credibility of this study. The chapter concludes with a section on my own reflexivity, as well as an outline of the ethical considerations related to the study.

4.2 Aims and objectives

The primary aim of this study was to explore, investigate, and document the subjective experience of fertility preservation among cancer survivors in South Africa. The objectives of the study were as follows: 1) to understand the factors that played a role in the decision-making process regarding fertility preservation, 2) to explore the process of fertility preservation among female cancer survivors in South Africa,3) to explore the emotional aspects of fertility preservation female cancer survivors in South Africa, 4) to explore the physical aspects of fertility preservation female cancer survivors in South Africa, and, 5) to explore fertility-related thoughts and concerns among women who received fertility. preservation.

4.3 Research approach

I chose a qualitative research design for this study because it is useful in exploring the experiences of individuals (Aspers & Corte, 2019; Bickman & Rog, 2014). In addition, qualitative studies are used to explore and understand individuals' beliefs, behaviours, and interactions, whereas quantitative investigations generate numerical data (Creswell, 2012). A qualitative approach provides the best opportunity to understand the innermost deliberations of individuals’ lived experiences (Alase, 2017). Since I attempted to explore the subjective experience of the process of fertility preservation it was necessary that participants were given the opportunity to share their lived experiences freely (Groenewald, 2004).

The flexibility of qualitative research allowed for participants in this study to describe their experiences of fertility preservation with depth and complexity (Creswell, 2006). The field of fertility preservation among oncology patients is a distinctive and new phenomenon, with no previous research reporting subjective information about a phenomenon in this specific population (Dyer et al., 2005). This is the gap that my study aimed to fill.

In this study I opted to use phenomenology as an approach. (Creswell, 2012) suggests five approaches to qualitative research, one being a phenomenological approach (the others are narrative, grounded theory, ethnographic and case study research). Using phenomenology as an approach allowed me to integrate an established theory as my theoretical framework and use thematic analysis, as opposed to interpretive phenomenological analysis (IPA), to analyse the data.

I found several studies that used the health belief model in conjunction with a phenomenological approach (see Azriful et al., 2021; Kaur, 2019). The purpose of phenomenology is to understand reality from individuals' narratives of their experiences and feelings, and to produce detailed descriptions of the phenomenon (Tufford & Newman, 2012). The health belief model’s six key constructs provided a priori framework to understand fertility preservation uptake as a health behaviour.

4.4 Participant selection and recruitment

Participants were women who underwent fertility preservation prior to receiving treatment for cancer. To be eligible to participate in the study, participants had to meet the following criteria: 1) be between the ages of 18-45 years, 2) have completed cancer treatment at least 6 months prior to being interviewed, 3) undergone fertility preservation prior to receiving cancer treatment, 4) be comfortable reading and responding in English/Afrikaans, and 5) reside in Cape Town or Johannesburg. Participants were excluded from this study if they: 1) did not undergo fertility preservation, 2) were not able to communicate in one of the two languages and 3) did not complete their cancer treatment more than 6 month ago.

4.4.1. Sampling and participant recruitment

Convenience sampling was utilized to recruit participants for this study. Convenience sampling is a type of non-probability sampling used when members of the target population are easily accessible, willing to participate, available at a given time, and geographically accessible (Etikan, 2016). Although participants were not easily accessible, they were willing to participate and geologically available. Participant recruitment was achieved by two methods. Initially a total of four fertility clinics within Cape Town and Johannesburg were contacted to assist with recruitment. However, I only managed to recruit participants at two of the clinics. These two cities were selected as I am currently based in Cape Town and my family is based in Johannesburg. I could therefore manage to travel between these cities for interviews.

Staff at each clinic assisted in recruiting the participants after familiarising themselves with the protocol outline in the study proposal. Based on the eligibility criteria, a sister/doctor at the fertility clinic reviewed their patient records and identified possible participants (i.e., patients who met the criteria for the study). Clinic staff then emailed the patients a recruitment information sheet (Appendix A). The information sheet instructed patients who were interested in learning more about the study to either contact the clinic, myself, or my supervisor. When patients contacted the clinic staff or my supervisor, they forwarded the patients' contact numbers or email addresses to me. Alternately, patients contacted me directly.

A total of 40 females were identified as meeting the criteria to participate in the study [N=26 (clinic 1) and N=14 (clinic 2)] and emailed the recruitment letter by a nurse from the clinic. A total of 15 participants showed interest in this study by responding to the recruitment email, however, only 13 of these patients were interviewed in total. Three interviews were excluded from the study based on the following reasons, 1) two completed their cancer treatment less than 6 months prior to being interviewed, 2) the patient who had undergone fertility preservation passed away and due to an unintentional error in the recruitment email sent from the clinic, the patients mother completed the interview. At the end, a total of 10 participants were included in the final data analysis. Of these, 8 interviews took place in-person and two took place online.

After several months of little success of participant recruitment, I obtained ethical clearance (appendix B) to recruit participants online using various social media platforms. I developed a flyer (appendix C) with a brief introduction to the study, inclusion criteria, and relevant contact numbers to advertise the study. This flyer was shared by The Cancer Association of South Africa (CANSA) and Oncology buddies on their social media platforms. Interested individuals had the option to contact myself, my supervisor, or the organisation if they wanted to participate in the study. Although the flyer yielded several potential participants, none of the women met the inclusion criteria, therefore resulting in no recruitment or interviews being conducted through social media recruiting.

4.4.2. Participant demographics

My final sample consisted of 10 participants who provided rich accounts of their experiences. The sample size was in accordance with the recommended sample size as per phenomenological approach guidelines (Aspers & Corte, 2019; Bickman & Rog, 2014; Manchester, 2011) and I was satisfied that I had reached saturation as no new information came from participants. The final ten participants' ages ranged from 26 to 42 years old, the mean age of the group was 31.6 years and the mean at the time of diagnosis was 29.6 years. All ten participants were employed full-time.

Table 1 contains the demographic characteristics of the participants in this study. Most participants did not have any biological children prior to receiving their cancer diagnosis and undergoing fertility preservation. More than half of the women were diagnosed with breast cancer. All the participants underwent chemotherapy, while several underwent radiation and surgery as well. Most of the women were married before receiving their diagnosis and remained married during both experiences. Only a few women reported having prior knowledge of assisted reproductive technologies, but their knowledge was limited.

Name	*Age at diagnosis*	*Age at interview*	*Employment*	*Children*	*Type of cancer*	*Cancer stage*	*Treatment*	*Relationship status during fertility preservation*	*Relationship status at interview*
Jane	30	32	Full time	1 from fertility preservation	Breast	3	Chemotherapy + Radiation + Double Mastectomy	Married	Married
Zandre	24	26	Full time	0	Ovarian	1	Chemotherapy	Single	Single
Jodi	26	30	Full time	0	Peripheral T-cell lymphoma	2	Chemotherapy	Relationship	In a new relationship
Caroline	28	29	Full time	0	Breast	3	Chemotherapy	Married	Married
Rochelle	28	30	Full time	0	Breast	3	Chemotherapy + Radiation + Double Mastectomy	Engaged	Single
Sam	29	31	Full time	1 from fertility preservation	Breast	2	Chemotherapy + Radiation	Married	Married
Nicole	40	42	Full time	1 before cancer	Breast	1	Chemotherapy + Radiation + Double Mastectomy	Married	Married
Lisa	29	30	Full time	1 before cancer	Breast	3	Chemotherapy + Radiation + Double Mastectomy	Married	Married
Jolene	29	30	Full time	0	Breast	2	Chemotherapy + Radiation + Double Mastectomy	Relationship	Single
Diane	33	36	Full time	1 from fertility preservation	Ovarian	1	Chemotherapy	Married	Married

Table 1: Demographic details of participants

4.4.3. Narrative description of participants

Jodi* was 30 years old at the time of the interview. She was 26 years at the time of her diagnosis and did not have any children. She was employed as an administrator. Jodi was diagnosed with stage 2, Peripheral T-cell lymphoma (PTCL). She underwent fertility preservation and harvested a total of 25 gametes prior to starting chemotherapy. She was in a relationship at the time of her diagnosis, however, the relationship ended due to her cancer process. She was in a new relationship at the time of the interview. Jodi reported that her cancer diagnosis came as a shock, that left her feeling angry, hopeless, and sad.

Zandre* was 26 years old at the time of the interview and 24 years at the time of her diagnosis. Zandre is a professional working in the manufacturing industry. She was diagnosed with stage 1, grade 3 ovarian cancer after a cyst removal. She underwent chemotherapy after harvesting 7 gametes through fertility preservation. At the time of her diagnosis and interview, she was still single. Zandre reported that after receiving her cancer diagnosis she was extremely sad and disappointed, however, fertility preservation was her “light at the end of this very dark tunnel (cancer diagnosis)”.

Diane* was 36 years old at the time of the interview and 33 years at the time of her diagnosis. At the time of the interview, she was working full-time a teacher. Diane was diagnosed with stage 1, grade 3 ovarian cancer. Before undergoing chemotherapy and two operations, Diane underwent fertility preservation and harvested 11 gametes. Diane’s emotional reaction towards her diagnosis included extreme anger, shock, and sadness, this could have been fuelled through their experience with cancer and fertility preservation when her partner was diagnosed twice with cancer. At the time of the interview Diane and her husband, successfully transplanted an embryo and she was 4 months pregnant.

Jolene* was 30 years old when interviewed and 29 years old when diagnosed with cancer. Jolene had a master's degree and worked in the family business. She was diagnosed with stage 2 breast cancer. and underwent several cancer treatment regimens such as chemotherapy, a double mastectomy, and 28 sessions of radiation. She successfully harvested 11 gametes. At the time of the diagnosis, she was in a steady relationship but was single when interviewed. For Jolene, the cancer diagnosis came as a shock, however, surviving the cancer was her main priority, at the same time she wanted to ensure that she had that "plan B" (fertility preservation).

Lisa* was 30 years old when interviewed and 29 years at the time of her diagnosis with stage 3 breast cancer. Lisa worked in human resources. She underwent fertility preservation and harvested 16 gametes, of which 11 embryos were preserved. She started undergoing chemotherapy and 32 sessions of radiation. Lisa stated that when she received her cancer diagnosis, she immediately went into fight mode. Lisa believed that while her diagnosis was a shock, she already had one child, but felt that she needed and wanted more children, which prompt her and her husband's decision to undergo fertility preservation despite having a higher risk cancer stage.

Nicole* was 42 years old when interviewed and 40 at the time of her diagnosis with stage 2 breast cancer. Nicole was a scientist. She stated that while she already had one child prior to her diagnosis she wanted more children. Nicole was married at the time of her diagnosis and the interview. Nicole underwent chemotherapy, a mastectomy, and radiation. For Nicole, the cancer diagnosis was a shock, however, she reported that she was not as concerned about the cancer, but more concerned about her future fertility.

Although, she has 16 preserved eggs, her husband and her have decided to donate her preserved material to science.

Sam* At the time of the interview Sam was 31 years old. She was 29 at the time of her diagnosis. Sam was diagnosed with stage 2 breast cancer and underwent several rounds of chemotherapy and radiation. She received her cancer diagnosis during her honeymoon, which came as a big shock and disappointment to her since her and her husband were planning on expanding their family. Sam was married and have had one successful pregnancy without using her preserved material. She currently has 10 gametes preserved.

Rochelle* was 30 years old at the time of the interview, and 28 at the time of her diagnosis. Rochelle was diagnosed with stage 1, but level 3 aggressive breast cancer. Rochelle worked in human resources. Rochelle underwent a double mastectomy, and chemotherapy as part of her cancer treatment. Due to a medical condition, Rochelle had to undergo surgery at a young age whereby one of her ovaries were removed, therefore, she only had one ovary at the time of her fertility preservation. Rochelle had a negative experience the first time while undergoing fertility preservation, therefore the second time she expressed feeling concerned and anxious about the procedure. For Rochelle, receiving a cancer diagnosis came as shock paired with feelings of anger and disappointment. Rochelle was engaged at the time of her diagnosis; however, she was single when interviewed.

Jane* At time of the interview Jane was 32 years old; she was 30 years old at the time of her diagnosis. At the time of the interview, Jane was working full-time in sales. She was diagnosed with stage 3 breast cancer. Jane harvested a total of 37 eggs, of which 20 were used to develop 3 embryos and 17 were preserved for later use. Jane underwent a double mastectomy and several rounds of chemotherapy. Jane stated that her cancer diagnosis came as a shock to her, but she quickly went into fight mode. Jane was married. At the time of the interview Jane and her husband had used one of their embryos and she had a biological child.

Caroline* was 29 years old when interviewed and reported that she was close to her 28th birthday when she was diagnosed with stage 3 breast cancer. She underwent several rounds of chemotherapy and is currently on hormone suppressants for the next five years, which she explained as being the worse thing ever. At the time of the diagnosis and interview she was still married. She stated that the process of fertility preservation was "bittersweet" for her, she was grateful that she was able to undergo the process, however, sad, anger and disappointed that she only harvested 4 gametes.

*****_All names are pseudonyms._

4.5 Data Collection

In qualitative studies, participants are experts of their own experiences (Moustakas, 2011). Researchers can gain in-depth information and an understanding of participants thoughts, feelings, and lived experiences through conducting face-to-face interviews (Aspers & Corte, 2019). According to (Alase, 2017) qualitative studies are considered approaches that are "participant orientated" (p.9), allowing for the interviewees (research participant) to express themselves while leaving room for adaptability and flexibility (Moustakas, 2011).

In keeping with the primary focus of qualitative studies, data collection for this study was done through in-depth, semi-structured interviews with women who underwent fertility preservation prior to receiving cancer treatment. According to (Adams, 2015), semi-structured interviews encourage a two-way communication between the researcher and the participant through means of open-ended and non-directive questions. In this study, the use of semi-structured interviews, gave me several opportunities to adjust questions and probe for in-depth information, while building rapport with the participant in a sensitive and empathic manner.

I used a semi-structured interview schedule consisting of two sections of questions to guide the interview (please refer to appendix D for interview schedule). Section one included several questions on the demographic attributes of participants. Section two explored the lived experience of fertility preservation. I asked participants about their thoughts and feelings before, during and after fertility preservation, their expectations of motherhood, fertility related concerns, the impact of fertility preservation (emotionally, physically, and socially), and the decision-making process. The questions generated and used elicited thick, detailed information on how participants experienced being diagnosed with cancer and undergoing fertility preservation. Interview questions were generated to be consistent and clear. The interview schedule questions were generated and informed by existing health and reproductive literature and studies. Moreover, I examined key aspects from other fertility preservation studies and attempted to expand on broad ideas and concepts that I had generated prior to setting up the interview schedule. I constructed the questions in the interview schedule to answer the aims and objectives of the study.

I attempted to avoid asking questions that were closed ended, double-barrelled, leading, and that used unconventional jargon (Adams, 2015). Ten interviews were conducted, of which seven interviews were conducted in English and three conducted in Afrikaans.

Interviews were either face-to-face (N=8) or online (N=2), depending on the preference of the participant. Both face-to-face and online participants were informed that all interviews were to be recorded and transcribed for data analysis purposes. All recordings were kept safe and secure with a password encryption on my personal device, to which only I and my supervisor and I had access. Participants were assured that each interview will be about 30-60 minutes long, allowing appropriate time and opportunity to share their experiences (interviews ranged from 38 – 76 minutes, average interview duration was 49.5 minutes).

During the face-to-face interviews, I tried to make the participants feel comfortable by providing them with the opportunity to settle down in the interview room and have a beverage while we engaged in light conversation. I used this time to provide the participants with some background information about myself and why their presence was important and appreciated. Once they settled in, I went through the information sheet with the participants prior to starting the recorded interview. The following was explained to every participant before their interview was conducted, 1) aim of the study, 2) ethical considerations, 3) potential risks involved in the study, 4) logistics of the study (such as duration of the interviews, 30-60 minutes), and 5) their rights as participant (right to withdraw from the study). Participants were given the opportunity to ask any questions or voice any concerns they had. I obtained written consent from the participants and then started the interviews.

The in-person interviews were conducted in a private office within the fertility clinic, or participants’ homes or boardrooms to ensure that they were comfortable and to ensure confidentiality.

Prior to conducting online interviews, I emailed the participants to set up a Skype interview at a time and place convenient to them. To ensure confidentiality, I conducted the interview in a private room in my personal residence, away from any possible interruptions or people. I emailed the information and consent sheet to the participant two days prior to the interview to allow for sufficient time for the participant to read, sign and return the signed consent document as well as ask or raise any questions or concerns they may have had. Subsequently, I proceeded to print the document sent from the participant and stored it the secure location along with all the other documents from previous interviews. At the start of the online interviews, I made sure that the participants were comfortable by engaging in small talk before moving onto the interview schedule. In addition, I discussed the information and consent sheet with the participant and answered any questions or concerns raised. Upon concluding of the interview (online and face-to-face), each participant was thanked for their time and willingness to share their experiences. Each participant was offered a R100 voucher as compensation for their time and effort. No participant withdrew from this study or expressed any serious signs of distress.

4.6 Data Analysis

Qualitative data analysis is frequently described as complex, ambiguous, and time-consuming (Seale, 2004). But also, as a creative and fascinating process whereby researchers can bring order, structure, and meaning to the mass of data collected (Ogino & Tanaka, 2014). In this study, the aim of the data analysis was to transform the qualitative data collected from research participants, into clear, insightful, understandable, and trustworthy findings (Nieuwenhuis, 2015).

According to Braun and Clark (2006) thematic analysis can be used to identify, analyse, and report recurring patterns, with the purpose of discovering themes and underlying meaning. By using thematic analysis, researchers can ensure rich and detailed presentation of data anchored on experiences and meaning making of the participants (Thomas & Harden, 2008).

Thematic analysis has proved useful in cases where a topic is under-researched, and for which a description of a phenomenon is required (Braun & Clarke, 2006). This makes thematic analysis especially applicable for this study, which dealt with a topic that has been largely unexplored. I used ATLAS.ti version 8 (Scientific Software Development, 2016) software programme to organise, code and visually display my data for analysis. Using ATLAS.ti provided me with the flexibility and opportunity to create codes, but also to visualise the coded data.

4.6.1. Applying thematic analysis

According to Braun and Clark (2006), before researchers can start with conducting thematic analysis, it is imperative for the researcher to decide between two different methods of analysis, namely inductive and deductive analyse. As conceptualized by Braun and Clark (2006), inductive analysis often rereferred to as a 'bottom up' approach that is driven by what is in the data, therefore codes and themes are derived from the content of the data. In contrast, a deductive approach often referred to as a 'top down' approach, means that the researcher brings to the data a series of pre-existing codes, ideas, concepts, or topics (Braun & Clarke, 2006). I decided to use both inductive and deductive thematic analysis approach, it provided me with the flexibility to determine codes based on the data and rely on pre-existing ideas, perceptions and concepts, giving a voice to the experiences and meaning making as described by the participants (Braun & Clarke, 2006).

Stage 1: According to Braun and Clark (2006) the aim of the first stage is to become intimately familiar with the data, during which researchers will notice important concepts that might be relevant to the research question. I was able to familiarise and immerse myself in the data by doing the interviews and transcriptions personally. I refrained from translating and correcting language errors to maintain meaning and truth to what the participant had said. I then listened to the recordings again and reviewed the transcripts to ensure accuracy of the transcriptions. I read through each interview again before uploading the document into ATLAS.ti for coding. During the process of transcribing, and re-reading, I had already begun to generate possible codes based on predominant concepts in the data, these were recorded on a separate word document.

Stage 2: The second step begins the systematic analysis process of the data through producing initial codes. I read through each transcript and coded interesting features and quotes across the dataset that either captured surface or hidden meaning (Braun & Clarke, 2006). One advantage of using ATLAS.ti was that I was able to carry out this step with ease by selecting the word/quotes within the document and assign a new or already created code.

Stage 3: In this phase, analysis starts to take shape as you shift from codes to generating themes. According to Braun and Clark (2006), a theme "captures something important about the data in relation to the research question and represents some level of patterned response or meaning within the dataset" (p.82). I reviewed the list of codes in ATLAS.ti and clustered codes together that shared some unifying similarity. I generated and colour coded several possible themes, each code was assigned a colour to indicate the broad theme. Before concluding this step, I merged, (re)named, and changed codes in order to refine and ensure consistency in the analysis (Braun & Clarke, 2006).

Stage 4: This stage involved a recursive process whereby the developed themes are reviewed in relation to the coded interview transcripts and the completed dataset. During this phase, I refined my themes that were developed in phase three. At this point in the analysis, I could decide which of the potential themes contained sufficient data to be considered an independent theme. Themes that did not contain sufficient data were merged into other themes that were more suitable. During this phase I created a mind map of all potential themes as well as codes that best described the theme.

Stage 5: Once I had chosen all the meaningful themes, I named them. I finalised the themes that were cultivated in the previous stage and provided detailed definitions and extracts from the transcribed text for each of the five themes to capture their meaning. According to (Braun & Clarke, 2006) a continuous analysis of the themes allows for the refinement of the particularities of each theme. Once I was satisfied that the themes represented the lived experience of fertility preservation among oncology patients, I finalized the names of each theme and sub-theme.

Stage 6: The sixth phase consisted of generating a report of the findings. During this process I selected rich compelling data extracts from the transcribed text that related to the research question, aims and objectives of this study (Braun & Clarke, 2006). In addition, I analysed my themes and refined my dataset through incorporating existing theory and literature pertaining to the findings, to strengthen the validity of my findings (Braun & Clarke, 2006).

During the data analysis there were several codes and phrases that were repeatedly generated. However, as Braun and Clark (2006) suggest, the purpose of the six phases in thematic analysis is to identify which of the codes, themes, and extracts that emerged during the analysis are relevant in answering the research question.

4.7 Trustworthiness of findings

According to (Connelly, 2016), trustworthiness, or as previously termed, rigor of a study refers to the degree of confidence in data, interpretation, and methods used to ensure the quality of a study. Moreover, it is necessary for researchers to establish the protocols and procedures that are necessary for a study to be considered worthy by readers (Gunawan, 2015). Although most experts agree that trustworthiness is necessary, several experts have debated as to what constitutes trustworthiness (Connelly, 2016). Gunawan (2015) outlines criteria to ensure trustworthiness, these outlines were accepted by most qualitative researchers. These criteria include credibility, transferability, dependability, and confirmability (Connelly, 2016).

The first criterion, credibility refers to the “congruence between the respondent’s opinions (reality), and the interpretations of the researcher (findings)” (Tobin & Begley, 2004). Credibility is demonstrated through several strategies such as participant checks, researcher objectivity, reflective journaling, prolonged engagement with participants, and persistent observations (Tobin & Begley, 2004). To confirm credibility in my study, my data analysis was reviewed by my supervisor to ensure that I made meaningful interpretations and that the presentation of the results were clear and concise.

During the interviews, I provided thorough descriptions of the participants, their responses, their behaviours, and the open-ended questions. Moreover, I sought clarification with participants when their responses were unclear to ensure that I had a full understanding of their responses. Furthermore, I tried to remain constantly aware at all times of my own assumptions, values, beliefs, and personal attributes that may have led to a biased interpretation of the data. To avoid this issue and ensure credibility I employed ‘bracketing’ a method that is used to mitigate the potential harmful effects of unacknowledged biases related to the research (Tufford & Newman, 2012). I attempted to safeguard the credibility of this study through encouraging participants to be honest during the interviews, constantly reminding them that there were no right or wrong answer and produced data as true and close to reality as possible. Additionally, (Shenton, 2004) notes that as an approach to widen the vision of the researcher frequent debriefing sessions with the supervisors are necessary. I had regular supervision sessions with my supervisor, which allowed me to discuss any concerns I may have experienced and share my reflections about the interview. My supervisor also listened to the audio recordings of my interviews and shared her perspectives with me.

The second criterion of ensuring trustworthiness, is the extent to which the data/findings of a study can be applied to other similar situations (Shenton, 2004). As Gunawan (2015) and (Shenton, 2004) note, the results of a qualitative study should be understood within the context of the characteristics of the study and its participants. To evaluate the extent to which findings of a study may be true in other settings, similar projects employing the same methods but conducted in different environments could well be of great value. Although, no previous study, such as this one has been recorded in South Africa, similar studies internationally revealed similar results (Shenton, 2004).

The third criterion of trustworthiness denotes the consistency with which the research procedure was carried out during the study (Shenton, 2004). However, researchers have noted due to the changing nature of the phenomena in qualitative studies, it might be difficult to achieve dependability (Shenton, 2004), and it might not be appropriate to the field of qualitative research (Gunawan, 2015). Nonetheless, to ensure dependability in this study, I always followed the sampling script and interview schedule to the best I could, to ensure technical consistency throughout the recruitment and data collection phases.

The final criterion, confirmability as outlined by (Shenton, 2004) note that researchers must “strive to ensure that the results reported are a reflection of the experiences and views of the participants, and not those of the researcher” (p.72). The author recognizes that difficulty lies in ensuring objectivity, since questionnaires are designed by the researcher therefore intrusion of biases are inevitable. (Gunawan, 2015) considers that a key criterion for confirmability is the extent to which the researcher admits his or her own biases. To certify confirmability, the researcher should provide descriptions of their own experiences by keeping a journal (Shenton, 2004). During my data collection process, I took great care in identifying any predispositions that may have come up and noted. I could then reflect on this once the interviews were completed, my reflexivity will be discussed later in this chapter.

Additionally, it is recommended that the researcher provide information regarding their training and preparation in the context of conducting qualitative research (Shenton, 2004). At this start of this research project, I had previously conducted a BASocSci Honours degree in counselling and communication. I attended several workshops and classes on conducting effective quantitative and qualitative studies, nonetheless, I was still relatively inexperienced in the field of oncology and fertility preservation. To prepare for this study I extensively researched and read on fertility preservation and oncology. Furthermore, I prepared thoroughly before each interview ensuring that I was familiar with the study protocol and questionnaire. In addition, prior to commencing with the interviews I received interview training from my supervisor. My supervisor was present during my first interview to guide me. By addressing the four-criterion set out by (Shenton, 2004) and (Gunawan, 2015), I was able to strengthen the trustworthiness of my study to my best abilities. While I did not have any personal familiarity or experience with what is being studied, this allowed me to be "ignorant" and placed the participant in the expert position, an empowering process (Berger, 2015).

4.8 Research reflexivity: the process of learning and unlearning

According to Dodgson (2019) reflexivity is a practise where researchers acknowledge that their own experiences, opinions, morals, and values will impact the context and meaning of a study. According to (Richardson, 1999), researcher reflexivity is an unavoidable and crucial aspect of trustworthiness that is essential for carrying out successful qualitative research. Conducting qualitative research, or more so fieldwork (interviews), changes a researcher in many ways (Palaganas et al., 2017). Reflexivity has been categorized into two separate sections namely, prospective, and retrospective reflexivity (Attia & Edge, 2017). Prospective reflexivity denotes the effects of the researcher on the study, this could include researchers' values and morals (Berger, 2015), pre-existing assumptions and beliefs about the phenomenon (Palaganas et al., 2017), social position (e.g., gender, age, race, immigration status, sexual orientation) (Berger, 2015) and personal experience (Attia & Edge, 2017). Retrospective reflexivity refers to the potential effects of the research process on the researcher (Attia & Edge, 2017).

By including a section on reflexivity, I can acknowledge how my personal beliefs, experiences, values, morals, social positioning, and assumptions could have influenced the study. Furthermore, it allows me to reflect on how the research process could have changed me, and how this change could have influenced the study (Berger, 2015). In keeping with the primary aim of prospective reflexivity, that is ensuring credibility of results through reducing the chances of the researcher biases influencing the study (Attia & Edge, 2017), I decided to perform several tasks to avoid this issue such as keeping an active journal (Vicary et al., 2017).

During the research process, I remained cognisant of my pre-dispositions as a novice researcher. Although my participants and I were women, between the ages of 20-35 years, I was slightly younger than most of the participants in this study and this may have contributed to me feeling intimidated at some point during the interview. This may be because of my pre-existing cultural believes, whereby age is a direct determination of power and experience. My personal history with cancer within my family may have shaped my current values and beliefs. However, I feel this allowed me to be more empathic with the participants and their process with cancer. Additionally, I did not have extensive knowledge on the medical aspects of oncology and fertility preservation, sharing this with my participants allowed for enhanced rapport building while gathering rich detailed data on their overall lived experience.

In addition, it was brought to my attention that several participants and I shared different views on two concepts, namely motherhood and religion. Being an open-minded person, I was able to see the participant as an individual with their own beliefs, values, and morals. To ensure that I represented the participant and their story as true as possible with an objective outlook, I was able to “bracket” (Tufford & Newman, 2012) my personal beliefs, values, and morals during the study. In keeping with the aim of retrospective reflexivity, I became significantly aware of how the research process impacted me and understanding these effects was an important part of the research process.

During the interviews, several participants revealed having experienced miscarriages before their diagnosis with cancer. This had a significant impact on me because my own mother dealt with several miscarriages before, and this had a tremendous impact on us as a family. In addition, the experiences of these women touched me on a personal level, because before starting this research process, I was fearful of being diagnosed with cancer. However, after interviewing these women my fear has reduced significantly, because I got a sense of hope and determination. I always left the fertility clinic with an emotionally drained but optimistic mindset.

This experience left me with concerning questions, but also left me feeling at ease with my own fear of cancer. I believe this research has allowed me to view cancer, motherhood, fertility, and fertility preservation in a different viewpoint. In the process of reflexivity, we, as researchers, are developing, strengthening, and changing our consciousness (Palaganas et al., 2017), while learning about ourselves as well as our participants (Berger, 2015). Being completely objective in a research study has been said to be an almost impossible task for human beings (Berger, 2015). However, (Dodgson, 2019) report that it is possible amongst participants and researchers to develop shared knowledge to better understand a phenomenon.

4.9 Ethical considerations

Before I started with recruitment and data collection, I obtained ethical approval (appendix E) from the Health and Research Ethics Committee (HREC) (reference number: S19/01/022, project ID 9024). Leading to the application for ethical clearance from the HREC, my supervisor and I attended meetings with various fertility specialist to procure support for this study (see appendix F for clinic approval letters). In addition, I obtained verbal permission from both the participating fertility clinics to conduct the interviews at their premises, in a safe and private room. To maintain client-clinic confidentiality, I did not have any access to client files from the clinics. The clinics operated as a first contact between me and the participants.

Online and face-to-face participants received a hard copy or email containing information about the study and consent prior to the interview, to ensure that they understood that the research process. Participants consented to participation by signing the informed consent form (appendix G). It was explained to each participant during the recruitment process that their participation in this study was entirely voluntary and that they could terminate the interview at any given time (information collected prior to withdrawal of the participant were to be deleted). I reassured participants that they had the right to share as much information as they were comfortable with or not answer any question if they were not up to it.

Participants were informed that they had to right to withdraw from the study at any given time, without facing any negative consequences. Furthermore, participants were informed that the interview would be recorded with their consent for data analysis purpose, however, the recordings were kept in a safe and secure location on my personal device, password encrypted. The electronic data obtained during this study (interview recordings and transcriptions) are stored on my personal password-protected device. Hard copies of the completed consent forms are stored in a locked cupboard that only I have access to. All electronical data will be deleted, and hard copies destroyed five years after completion of the study.

Moreover, participants were reassured that any information they share within the interview room would be kept confidential and would not be shared or discussed with anyone other than my supervisor. Participants were informed that the study was taking place independent of the fertility clinic and that the information provided will not be shared with the fertility clinic. Doctors at the clinic were not informed which patients participated and which declined participation.

No one-except for my supervisor and I had access to the completed demographic, transcriptions, and recordings as they were stored electronically on my personal computer, which is password-locked. During the data analysis, anonymity was maintained by means of pseudonyms, meaning that no participant could potentially be identified in the final paper by their real names, or any other detailed information. As this study dealt with sensitive content, it could have been possible that some participants experienced trauma or distress. Therefore, contact details of the necessary referrals were listed in the information/consent sheet for their convenience if they felt it was needed. According to the HREC guidelines, all participants were compensated for their time, inconvenience, and expenses, by means of a R100 pick and pay voucher for and R50 for travelling expenses, where necessary.

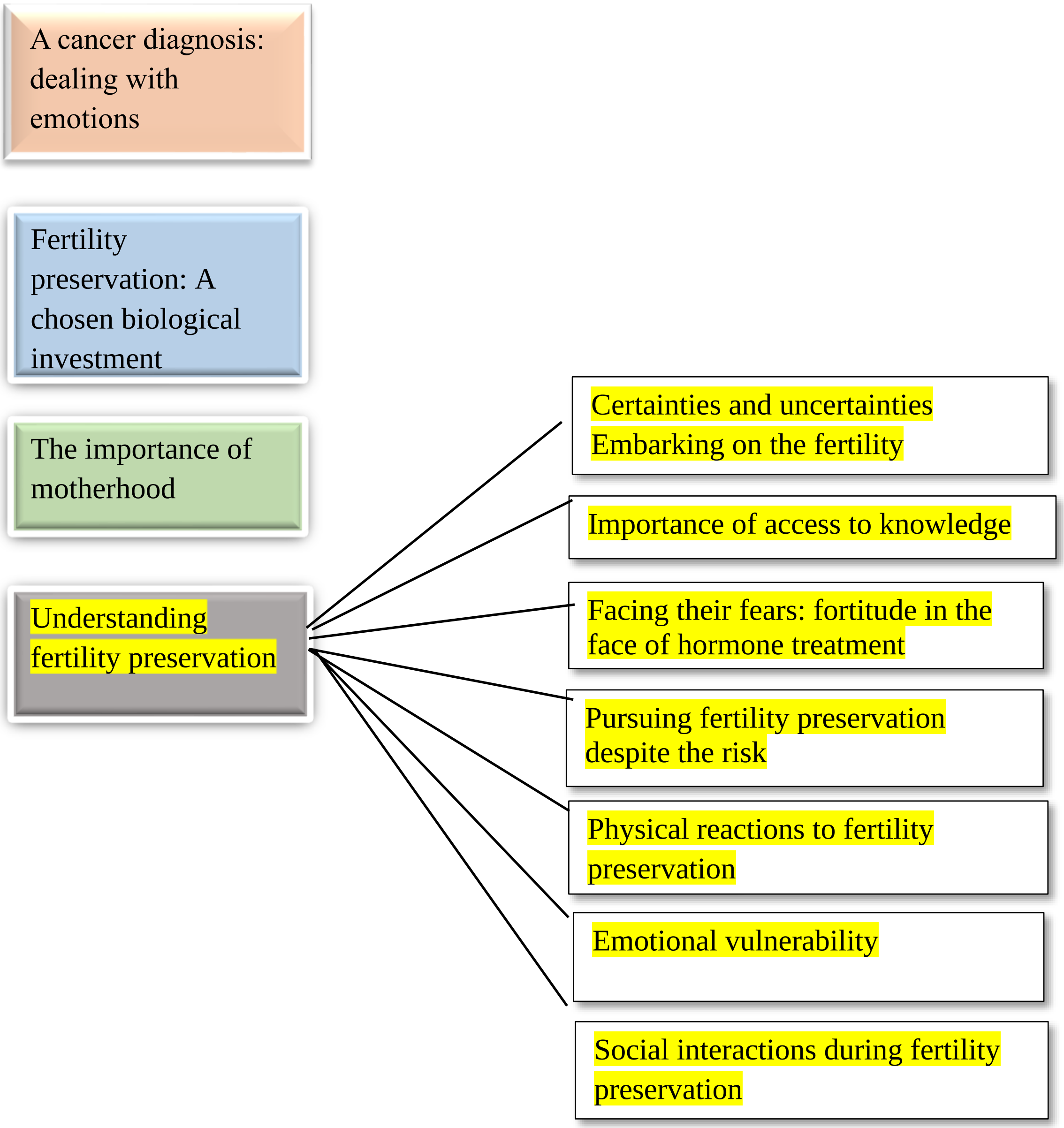
4.10 Conclusion

In this chapter, I provided a detailed outline of the present study's research design, participant recruitment, data collection strategy, data analysis techniques reflexivity, and the ethical considerations that were applied throughout the study. The next chapter contains the findings of this study.

Chapter 5: Results

5.1 Introduction

The purpose of this study was to explore the subjective experience of fertility preservation among female cancer survivors within private fertility clinics in South Africa. Ten semi-structured interviews were conducted and analysed using thematic analysis. I identified five themes, namely, 1) a cancer diagnosis: dealing with emotions; 2) fertility preservation: a chosen biological investment; 3) the importance of motherhood; 4) understanding fertility preservation; and 5) thought processes and coping skills during the fertility preservation process.



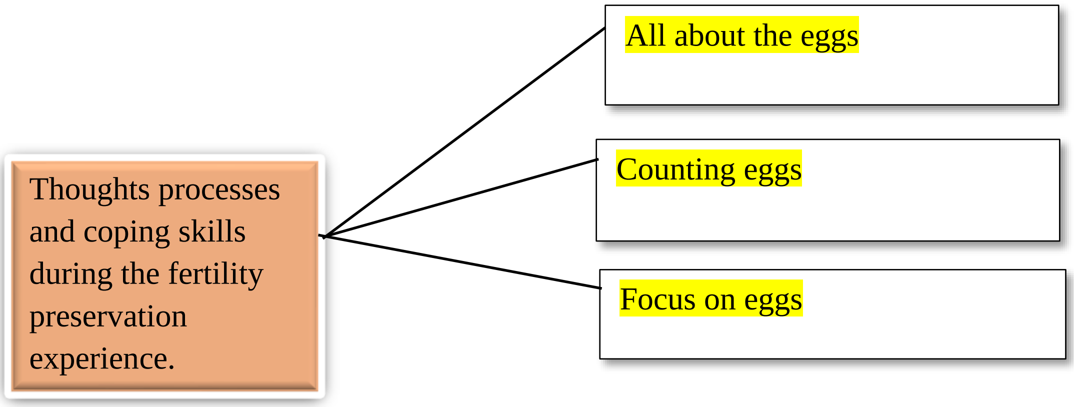


Figure 1: Visual description of findings

5.2 A cancer diagnosis: dealing with emotions

Before describing participants decisions to opt for fertility preservation, I will briefly describe different emotional reactions to their cancer diagnosis, as this provides the context in which these decisions were made. During the interviews women in this study usually started by describing their experiences of being diagnosed with cancer. Their reactions to their diagnosis varied, with most stating that they did not expect a positive cancer diagnosis. Participants also named and described their emotional reactions to the diagnosis. These emotions included shock, anxiety, fear, anger, hopelessness, disappointment, and sadness. Several women reported that they experienced a sense of denial to avoid the fear, anxiousness, and sadness they regarding their diagnosis. For example, Nicole, a 42-year-old woman, working in the medical research science field stated that when she found a lump in her breast, she initially thought it was an enlarged muscle. She described the day of her diagnosis as an ordinary day and regarded her diagnostic appointment with her doctor as an errand, this is displayed in the following quotation:

I said, oh I (must) leave quickly, to go get my diagnosis, I will be back at the testing station (research), we were so busy with patients... Anyway, so then we found out it is breast cancer

Nicole regarded her visit to the doctor to receive her results as a quick assignment that needed to be done during her "lunch break". After receiving her diagnosis, she went back to work and continued working. For example, due to the initial unexpectedness of their cancer diagnosis, some women reported feeling emotionally numb and shocked, while others reported experiencing very little emotions at the time of their diagnosis. Nicole narrates her surprise at the diagnosis in the following quotation from the interview:

> *…when I got the diagnosis, it was very unexpected, nobody could think that it would have been that (cancer) you know... very unexpected.*

Another participant, Diane, 36-year-old woman, whose husband was diagnosed with stage 4 bone marrow cancer and who relapsed shortly prior to her receiving her diagnosis, stated that she was extremely "angry" when she was diagnosed. She explained that her anger was driven from the fact that she had recently went to the fertility clinic to undergo an ultrasound in preparation for artificial insemination with her husband's frozen sperm cells when the doctor discovered a cyst on her ovary. Diane underwent surgery to remove the cyst and was diagnosed with stage 2 ovarian cancer a few days after the procedure. Diane explained that when she got her diagnosis, she experienced an instant feeling of depression and anger. This is exemplified in the following interview extract from Diane's interview:

I was not in a good space, like I went into instant depression and I was angry, and.... because of what had happened to him [referring to partner's cancer], I was just like this cannot be happening again' [being diagnosed with cancer] and uhm…the doctor had originally, and he is good oncologist, and gyno, he is professor and he has said he doesn't *think it is cancerous, because it is unilateral (only 1 ovary had a cyst on) so I was in two minds about it- but when John came home, I could see on his face...he had been crying...and he said to me it is bad news…*

Diane stated that she felt relatively safe that it would not be cancer (the doctor at the fertility clinic told Diane that it may be a cyst) however, when she received her diagnosis, she experienced temporary hostility and disbelief about her diagnosis. Several participants reported that in addition to the initial emotions, they also experienced a wide range of emotions throughout their cancer trajectory, such as feelings of depression, hopelessness, anger, and intense sadness. The women maintained that these emotional reactions were often so overpowering and overwhelming that they were sometimes too difficult to confront. In the following statement, Caroline describes how she ignored to cope with feelings and thoughts that were overwhelming:

I think that [anxiety medication] sort of helped me numb everything you know… (laughing). uhm which I was grateful for, I mean I had to process a lot and ja trying to…uhm ja.

Caroline explained that she felt grateful that she was able to contain undesirable and overwhelming feelings and thoughts during her cancer treatment and fertility preservation. Similarly, Diane noted that during the entire fertility preservation process she felt like a "zombie and numb", this could possibly imply that they used mental disengagement to cope. Diane's disengagement from her own experience could have been fuelled by her and her husband's experience with cancer or may indicate emotional exhaustion, having to navigate and fight two cancer experiences. In the following statement Diane described this exhaustion:

> *I think it [is] very different if it is one person in the relationship if you look at if, as a bit more fighting for yourself, but I fought for a whole year with his cancer and then I had to fight for mine…so I fought for the both of us…I was so numb…and just tired.*

In addition to Diane's statement, the other participants recalled their initial feelings associated with receiving their diagnosis. These emotional reactions to the initial diagnosis included feeling overwhelmed, sad, scared, and anxious. In this theme I reported on the wide range of emotions that underpinned participants experienced when they were diagnosed with cancer to give an impression of the context in which participants undertook the decision to undergo fertility preservation.

5.3 Fertility preservation: A chosen biological investment

Participants reflected on choosing between immediate cancer treatments and delaying the cancer treatment to accommodate for fertility preservation. Some of the women in this study stated that they had a sense of urgency to start their cancer treatment to avoid any potential risks of the cancer spreading and quite possibly death. However, all the women in this study undertook fertility preservation regardless of the potential risks involved. For these women, cancer treatment was an important priority however, future motherhood was an even more important priority.

The urgency that women faced meant that they had little time available to them to decide on certain practicalities. These practicalities include which doctors and medical practices they consulted. Most participants were satisfied with their fertility preservation processes. However, some reported that they were not completely satisfied and would have preferred some more time to make a better-informed decision. For example, Nel, diagnosed with stage 2, breast cancer stated that she did not feel completely comfortable with the bedside manner of the first doctor (fertility specialist) during her initial consultation. She stated that she did not have much time to find another doctor because she was diagnosed with an aggressive cancer and needed to start fertility treatment and cancer treatment promptly. She added that she only had one opportunity to produce and harvest her gametes. She conveys this urgency in the following interview extract:

…and I didn't feel right, so but in the meantime, clock was ticking (be)cause I also know [knew] that I had to start my chemo. I had just one cycle and then I had to start my chemo [chemotherapy]…I could not delay it [chemotherapy].

The sense of urgency to undergo fertility preservation was also reported by Jane and Jolene, who were diagnosed with aggressive, advanced stage cancers. Despite the urgency related to having aggressive advanced cancers, both opted to delay cancer treatment to accommodate for fertility preservation, again possibly showcasing the importance of motherhood. They stated that they wanted to start with the fertility preservation as soon possible so that they could start cancer treatments promptly as they feared the cancer metastasising. This sentiment is captured in the following statement by Jolene, who was 30 years old at the time of the interview:

…because I wanted to start my treatment [for cancer] ASAP in the fear of it spreading ...so but ja...ugh I just took it as it comes...I did not have much time.

The decision to delay cancer treatment to accommodate for fertility preservation was not always well-received by oncologists. Some participants explained that they found themselves in a dilemma, where their decisions were not always fully supported by oncologists. This may be because oncologists were focused on treating cancer and did not have a holistic view of patients' needs, such as future biological motherhood. For example, Jane, a 32-year-old female, with a history of a miscarriage and no prior children explained that her oncologist was more concerned about her health and the cancer spreading whereas starting a family was more important to her. However, she found the support that she needed from her breast surgeon who identified her need for fertility preservation. She further stated that the surgeon "saw me as person needing this [fertility preservation]" and "understood the importance for me to have a child", even if it meant delaying cancer treatment and risking metastasis. Diane had a similar experience and stated the following regarding her priorities in relation to both the oncologist and fertility specialist's priorities:

> *They [doctors at the fertility clinic] actually wanted to do another egg retrieval [the first egg retrieval failed] so they wanted to stimulate again and take more eggs out, because they only got 11 the first time…I wanted it, because the doctor said I only had 1 ovary, but the oncologist said there was not enough time so she wanted to start the chemotherapy,… we could not wait longer to start treatment….*

Diane stated that she was given Zoledex, [pre-menopausal injection that suppresses the ovary from producing eggs] before going for cancer treatment, as a precaution to protect her ovary during cancer treatment. Diane stated that under normal circumstances they would give the Zoledex injection to patients with breast cancer, however, the doctor [at the fertility clinic] suggested this protocol for Diane and her husband. Diane reported that the hormone suppressant that she received prior to cancer treatment, was effective and that she regained full functioning of her ovary and menstruated two months after completing cancer treatment without side-effects. Her doctors successfully retrieved her eggs, which were fertilized with her husband's sperm. The embryo was transplanted successfully back into Diane, who was pregnant at the time of the interview. Diane described the process as "very complex with a lot of going back and forth among the doctors and myself....". However, despite the tireless efforts she and her husband went through she regarded the process as, "worth it" as it resulted in her becoming pregnant and fulfilling her motherhood wish.

The cancer diagnosis also meant that future plans had to be amended for some participants. For example, Diane, who got married four months prior to her husband's cancer diagnosis explained that they were not yet ready at the time to start a family and wanted to wait a few years before starting a family. However, some of the women such as Sam, Lisa and Nicole clarified that they did not want to delay motherhood and wanted to become pregnant promptly after getting married due to their age at time of marriage. For example, Sam conveys the urgency to fall pregnant after getting married in the following extract:

Jim [Sam's husband] and I, (while) on honeymoon, I left my pill [contraceptive pill], and we said we are just going to let go, (be)cause some people really struggle [to fall pregnant], and if it happens [become pregnant], it happens…and then ja that happened. [Sam received her cancer diagnosis while they were on honeymoon (translated from Afrikaans).

When confronted with the possibility of being infertile after cancer treatment, all the women expressed a sense of urgency to undergo fertility treatment while delaying their cancer treatment to secure a future that include could biological motherhood. For example, Jodi recalled that before being diagnosed with cancer, having children was not something that was on her mind, however this all changed when she received her diagnosis, and the ability was threatened. This following interview extract recalls the change of mindset of Jodi:

Stuff like this (concerns about kids) does not cross your mind, you know, until that one day when you are like confronted with it (possible infertile due to cancer). It (life) changes forever.... and ja so...I started the fertility treatment. Everything just happened so quickly.

Rochelle, a 30-year-old female recalled that when she was diagnosed with cancer at age 29, she was considering whether being a mother was something she wanted for herself in the future. She explained that she knew that she wanted the option of having her own children but at that stage in her life she was not certain. The sentiment is captured in the following interview extract by Rochelle, who at the time of the interview had undergone two rounds of fertility treatment:

The funny thing is when all of my stuff happened I did not even know I wanted children, like I knew I wanted the option of having my own children but I was not certain when ja…its weird…but I think in my subconscious you know I wanted it (motherhood) but the time of my life was wrong but I want that option open and when you hear the (ability) being taken away from you…its kinds hits you and like you never think about the luxury of being able to have your own child. I love kids…I know now I really want kids.

Although Rochelle had some uncertainty about the importance for motherhood, she underwent fertility preservation twice before undergoing cancer treatment. She recalls that she realised that motherhood was something that she values deeply.

Several of the women from this study explained that they did not have extensive knowledge of fertility preservation. For example, Nicole noted that even though her knowledge was “limited”, fertility preservation was “something that needed to be done, if that is what it takes to have my own children one day”. More than a half of the women such as Jodi, Diane, Jane, and Sam, described feeling anxious, confused, and overwhelmed with the process due to their lack of knowledge. Sam reported that she felt overwhelmed with her cancer diagnosis and possible infertility. Sam was unable to think about the physical and emotional demands of this process in a rational and practical manner, she therefore relied exclusively relied on the doctors' recommendations. Similarly, Jane noted that she left her consultation with some information on fertility preservation, but explained that the following:

You never know what to expect when you go into this process...you know one that is a bit unsure…and you there is not much (information)

Similarly, Jodi explained that even though she did not feel like there was enough research on fertility preservation, she still valued future motherhood highly and therefore underwent fertility preservation. In the following interview segment from Jodi, she recalls on the lack of research on fertility preservation and her feelings associated with this:

It (fertility preservation) was a massive relief, for like a future motherhood, like obviously still scared and anxious because of the situation I was in (cancer), and unsure about the unknown because there is not a lot of info on this stuff (fertility preservation and cancer).

Several of the women explained that due to the value they placed on potentially having biological children in the future and the lack of knowledge or experience, they ended up following instructions from fertility specialists, oncologists, and surgeons, without any hesitation. For example, Diane, described feeling like a robot, who was "just following orders" out of desperation while feeling overwhelmed. In the following interview extract, Diane describes her behaviour:

Yes, you do not think or question anything, you are like a robot, someone says you need to go and drink that, you do it and if they say you go and do that you do it…you just so desperate to do this (fertility preservation) and survive, you don't even think, you just do …so (shoulder shrug).

A few of the other women (Sam, Jane, and Jodi) stated that, they also just had to go through with the fertility preservation process as, they literally did not have the time or mental space to question anything set out for them to do, such as injecting themselves with hormones, which none of the women knew specifics about. For women, such as Jolene, and Nicole, coming from a scientific medical background aided them with some prior knowledge of fertility preservation which made them feel more at ease and trusting of the process. While most of the participants had limited knowledge of assisted reproductive technology, such as in-vitro-fertilization for couples who suffer from infertility, some of the women reported not knowing about the possibility for fertility preservation among cancer patients.

Although not always spoken about in an open manner, several of the women explained that they were not aware of any potential risks involved in undergoing fertility preservation process. Some women, like Nicole, Sam, Diane, and Jodi concluded that they felt overwhelmed with their diagnosis, and this may have contributed to missed conversations between them and their fertility specialists that might have that included the potential risks involved. For example, Nicole, stated that she “didn’t know of any risks involved in undergoing fertility preservation” and that her “brain was not 100 percent at the time, and I did not hear anything”. Like Nicole, several of the women explained that although they were overwhelmed with everything that was happening to them, the only thing that made sense was to opt for fertility preservation, regardless of everything else that was happening.

In this theme, women reflected on the decision they made between receiving immediate cancer treatments or delaying their cancer treatment to accommodate for fertility preservation to secure a future that includes biological motherhood. I demonstrated that in this theme that participants expressed feeling overwhelmed, anxious, and confused due to the lack of research and their limited knowledge on fertility preservation. For some women, like Diane, due to time constraints and lack of knowledge they relied on orders from healthcare professionals and fertility specialists. Despite any known and/or unknown potential risks involved in the uptake of fertility preservation, all the participants chose to undergo fertility preservation regardless. All the women described being content and satisfied with their choice and the outcome, despite suffering some significant setbacks for two of the women, namely, Rochelle and Diane.

5.4 The importance of motherhood

Motherhood is commonly perceived as being a fundamental goal and instinctual for women. The aspiration for biological motherhood is considered inevitable, unquestioned, and central to "completing the circle [of life]" as described by Diane. All the participants indicated that motherhood was an important personal life goal for them, and that the dream of motherhood is best realized through biological reproduction. For some women, like Diane it was "biological child or no child at all". The importance of biological motherhood among all the participants was the driving force in the uptake of fertility preservation and delaying their cancer treatment. For women, such as Caroline, Zandre and Diane, not being able to achieve motherhood would have meant that a "part of them" (Caroline) would have been lost or taken away as motherhood was essential to being a woman. For example, in the following interview extract Zandre clarifies the impact her possible infertility due to cancer treatment may have had on her perception of what it meant being a woman:

My biggest heart's desire was to be a mother one day, and I would like to carry my own children, but uhm…so that was my biggest concern and it felt like if I was not able to do this a big part of my womanhood would be gone (translated from Afrikaans).

For several of the women such as Zandre, Caroline, Jane and Diane, having a biological child was a defining aspect in their identity as women. Future fertility was a noteworthy concern for many women in this study, with some of them specifying that future biological motherhood was more important to them than the cancer. For example, Nicole, 42-year-old women and mother to a three-year-old boy shared the following with regards to the importance of biological motherhood over the cancer:

When I heard the (my) diagnosis breast cancer, my biggest thing was, (the) first thing that I heard (in my head) was I can't get another child ... not the breast cancer... the not going to be able to get a second child was the biggest thing (concern). And everyone was like the breast cancer, and .... I was like I want another child; I do not care about the cancer (laughing)...

Similarly, Lisa, a 30-year-old woman and mother to a four-year-old girl shared the following about the importance for motherhood for her:

Uhm I believe that the Lord gives you a need and he fill your heart full of love so that you can share it with others…so I yes… I always wanted children… [children] (translated from Afrikaans).

The decision to undergo fertility preservation to ensure future biological motherhood was so important for some participants that it outweighed everything else, such as costs involved, potential risks, and delaying cancer treatment. For example, Nicole shared the following about the importance of motherhood regardless of the costs involved:

Like the biggest thing was I wanted a child, and like financially, we did not think of the money and would have done it even if it did cost seventy thousand [rand], you have a child... you do not think of the money...

Achieving motherhood was enormously important for Nicole, Sam, Caroline, and Diane regardless of the monetary sacrifices they had to make to undergo fertility preservation in the hope of future motherhood. For example, Sam noted that she and her husband used their wedding gift money, which was supposed to contribute to a deposit on their first property, to pay for fertility preservation. Similarly, Diane explained a sacrifice made for motherhood in the following extract:

I mean that is your deposit for a house [undergoing fertility preservation, artificial insemination, and in vitro-fertilization], you know we still live in a tiny place, it's just how it's been (Diane and her husband reported spent roughly R 250 000 on the fertility preservation)

Some participants who did not have any children prior to having cancer, they stated that they always aspired to be mothers, with some stating that this was their intention since they were teenagers. Jodi recalls the devastating effect the financial costs associated with fertility preservation had on her wishes of becoming a mother in the following interview extract:

I always wanted kids since I was a teenager, I wanted to be a mom so when they told me this (potential infertility from cancer), I left the chemo lab, I went to the fertility lab, they told me how much it was going to cost and I went downstairs started and I just cried....I cried because....I don't have the money to do this treatment and you know its like this is my dream.

Jodi felt like her teenage dreams of becoming a mother and having her own family was shattered by the costs associated with fertility preservation. For Jodi, "uncontrollably crying" was her expression of the importance of motherhood for her. Jodi was able to secure a loan through her previous employer to pay for her fertility preservation. For a few women, such as Nicole, Sam, Lisa, Jodi, and Jane their wish for more than one child was the driving force for them in the uptake of fertility preservation. For example, Lisa stated the following when asked about her need to have more children: *Yes, yes, I would love to have like 15 of them I could* (Translated from Afrikaans). However, Jolene, a 30-year-old female with triple negative breast cancer and no children at the time of the interview explained the following when asked about her plans for children in the future:

"Ja pretty much...uhm...ugh never wanted like...the whole nursery of kids (laughing)...just maybe one or two kids...at the most but ja something...I have always loved kids and... wanted to be a mom one day..."

Nicole, who already had a three-year-old son before being diagnosed with cancer and who suffered a miscarriage prior to her diagnosis described the importance of a second child to her and her emotional responses in the following interview extract:

"There is no doubt, I wanted a second child, a sibling for my son…the biggest thing was I wanted a child…you know like have a second child…it was the most important, [I felt] being anxious, and sad that I could (possibly) not provide my son with a sibling, disappointed".

As explained by Nicole in the statement above, losing her sense of motherhood and not being able to provide her son with a sibling was associated with feelings of failure, disappointment, and anxiety. In addition, some women reported they would have felt angry, distraught, sad, and broken if they were not able to achieve biological motherhood. Jane, who has suffered from a miscarriage before being diagnosed with cancer reflected on her emotional response and well-being on what fertility preservation and the possibility of future motherhood meant to her:

I was completely happy that we could do this (fertility preservation) ...cause all I wanted in my life, was to have children, I have always known that and... just completely blessed to have that option (fertility preservation) ... Ja and like if (I) couldn't (have a baby) ...I would be broken.

Although motherhood was regarded as significant for all the participants in this study, and most of them expressed having a maternal instinct, Diane stated that being maternal did not come naturally. Diane, reflected on her personal maternal expectation in the following interview extract:

I am not a maternal person at heart, like when I hold someone else's child, I don't yearn for a baby, I have never been like that, I am a very soft person but I am not...like you know (some) women are like "OMW I just want to have a baby", and I have never been...but John (pseudonym for her husband)...like if this was going to go down (having a child)....like when it is your own (biological motherhood), it is different.

Diane, and her husband decided prior to them receiving their cancer diagnoses that having a biological child was their only choice and that if biological parenthood was not meant to be, they would not be pursue any other alternatives (such as adoption). Diane reflected on the beliefs and importance of having a biological child and in the following interview extract:

He (partner) had spoken to me before even gotten married he said it (biological child) is (a) deal breaker, so we are not adopting, like if we don't have a biological child, then it is *just not for us....and that was before we knew about the cancer...and when we got the cancer...and we spoke about it, and he said he still does not want adopt and I was with him, if we can't have a biological child, then we are not having children, and I felt the same...and that was our only choice, biological children or nothing…*

Although the concept of motherhood was highly valued by all the women in this study. For some women, such as Diane and Zandre the option of adoption was just not the same as biological children. Two participants [Diane and Jolene] stated that would have accepted it if their fertility preservation were unsuccessful. Diane stated that if biological motherhood, did not happen, she would have been really upset and angry but "eventually" with time she would have accepted it.

Jolene, who was single at the time of the interview, explained that she did the fertility preservation as precaution in the event of her personal need for motherhood in the future. Having said this, Jolene explained that if the fertility preservation was not successful, she would too, like Diane would have accepted it, if this meant she was able to recover and live cancer free regardless. This thought is captured in the following statement by Jolene, who was cancer free at the time of the interview

Like although I always wanted kids...like I... I would not say that I accepted it (infertility) already... but if it was just meant to be because of everything (cancer) I would have accepted it and I would have been fine as long as I got better and dealt with the cancer and actually move on and live after the whole story...

Jolene and Diane reported that becoming a mother was important, and that recovering and living healthy post-cancer was just as significant for them as motherhood. For Jolene, having her gametes frozen produced a similar feeling to that of having a "time capsule", which she could make use of when she felt the time was right to pursue biological motherhood. Some participants, such as Jane, Caroline and Diane reported that their frozen gametes were the "cherry on the cake" to end this horrifying and life-threating process.

Diane, who at the time of the interview was pregnant from her second attempt of in-vitro-fertilization explained the following with regards to "ending off" the cancer and fertility preservation process:

"...I want to (be hopeful) but I want to see if this little one is okay...that could be.... that could be what makes this circle round...ja so.it is important…it completes the circle of everything and us... it (fertility preservation) just made it so right, we always wanted kids."

All but one of the women stated that her husband's need for parenthood was as significant for her as her own need for motherhood. Undergoing fertility preservation was important to secure a future that included motherhood, for many participants this was best achieved through biological reproduction. For all the participants from this study, future motherhood was the driving force in the uptake of fertility preservation, regardless of any potential risks, or costs associated with it.

For one participant, possibly being infertile had more significant impact on her than the cancer, similarly another participant noted that she would be distraught if she were not able to fulfil her dreams of having a biological child. For one participant, Diane, achieving biological motherhood was significantly important to her and her husband and this would be the only option for them, biological child, or no child at all.

5.5 Understanding fertility preservation

Participants reflected on their personal experiences of the fertility preservation process, this included undergoing and administering hormone therapy, and subsequently undergoing a surgical procedure to harvest their gametes. In this theme I will discuss seven sub-themes that pertain to the experience of fertility preservation, namely, certainties and uncertainties: embarking on the fertility preservation process, importance of access to knowledge, facing their fears: fortitude in the face of hormone treatment, fertility preservation: potential risks involved, physical reactions to fertility preservation, emotional vulnerability, social interactions during fertility preservation.

5.5.1. Certainties and uncertainties: Embarking on the process

Participants in this study reflected on their appreciation for the opportunity to undergo fertility preservation before commencing with cancer treatment. Having said this some of the women expressed feeling anxious and scared before beginning with hormone therapy for fertility preservation as the outcome was unpredictable. For a few women, such as Jane, Jodi, Sam, and Jolene the process of undergoing hormone therapy brought upon fear and anxiety regarding potential risks involved, such as the cancer possibly metastasizing due to hormone therapy medication. For example, Jane reflected on her feelings around using hormone therapy in the following interview extract:

I was a bit nervous about putting all those hormones in my body…and what this could do you know (to the cancer) … but I knew it had to be done…

It is evident that although some women expressed feeling nervous and anxious about the potential risks involved with undergoing hormone treatment, all the women remained committed to the procedure, since they felt that hormone therapy was their only option, and because they trusted their doctors. Other reactions to undergoing hormone therapy included feeling confused, unsure, and scared about the process. Many of the women, such as Jodi, Nicole and Jane expressed that there was not enough information on what they could expect when undergoing hormone therapy. Jodi recalled during the interview that although preserving her fertility was important to her, she was nervous and confused about what to expect in the process, a sentiment confirmed by other participants.

5.5.2. Importance of access to knowledge

Before embarking on the fertility preservation process, women reported that they reflected on the information or lack thereof regarding fertility preservation. Women, such as Jodi, Nicole and Jane expressed that there was not enough information on what they could expect when undergoing hormone therapy. For example, Rochelle reported that the lack of information from the fertility clinic on the negative side effects of the fertility preservation left her feeling unsupported and scared. She coveys her frustration in the following interview segment:

> *It was not okay to be in pain for fu$$king 6 hours and they could not do anything about it. NO…. have some f$$king sense of empathy and understanding…Like they could have told me this before the time you know…. like this might happen, surely like they are the experts they should have known something like this (hypertension) could happen.*

Rochelle expressed feeling frustrated due to the lack of empathy and support she received from the fertility nurses at the clinic regarding the side-effects she experienced following her egg harvesting procedure. Furthermore, Rochelle explained how she understood the side effects following feeling “dismissed” by the nurses from the clinic:

> *Google told me that I was experiencing hypertension, like I am that 2% of which this may happen to, but I mean they could have told me that something like this, as rare as it may be…like I was already sacred as it is.*

Rochelle and Jodi both reported that although fertility preservation was important, they would have appreciated some additional support and information during their hormone treatment and gamete harvesting procedure. Jodi recalled feeling “anxious” and “scared” during the process as she was not completely “clued” up with the fertility preservation procedure. Fertility specialists failed to mention certain fertility sparing techniques. According to Sam the “option of an embryo” (egg fertilization and frozen) was never mentioned to her during her consultation with the fertility specialist. Sam reported that if she had known about this option prior to her egg harvesting, she might have felt more secure and content with her future fertility. Women from this study reported that information was a key aspect, and many had different levels of satisfaction with the information that doctors shared with them.

5.5.3. Facing their fears: fortitude in the face of hormone treatment

Before the women underwent the procedure of harvesting their gametes, they were required to undergo hormone therapy that required them to inject themselves for roughly two weeks with hormones to mature gametes for harvesting. Majority of the women recalled the process of injecting themselves as not always straightforward and many felt confused and anxious about what was required. For example, Rochelle stated that she had a fear of needles and that her fear associated with fertility preservation was due to the hormone therapy injections. She described her fear in the following interview:

I have a fear….uhm well I (had) a fear of needles so telling me that I had to inject myself in the morning and evenings is not a joke….but I am sure the needles (injections) had to do with it mostly (extreme fear and anxiety) but I don't think the fertility preservation was the biggest thing, I think it was the fact that I needed to do injections…I had like a huge fear you know…it was not funny…it really burnt a lot.

Similarly, another participant, Jane, recalled how difficult the injections were in the following extract taken from the interview:

Ja it was flippen hard, it (hormone therapy injections) was not fun...those injections were...uhm you know you have to inject yourself and then uhm...how your body response is quite hectic…like it physically affects you…but it ja , it was very painful but luckily he (Jane's husband) was there to help me inject…

For several participants such as Sam it was challenging to ask and accept assistance from her husband and/or friends to perform the hormone injections for her. Sam acknowledged that she had always been an independent person and did not want to be a "nuisance" to anyone. Based on this she "sucked-it up" and did the injections herself on most occasions, but she remembered feeling overwhelmed, as she too reported a fear of needles. In the following interview extract Sam recalls on the first time she attempted to perform the hormone injections herself so that she could avoid asking for assistance:

I could not ask someone every morning to inject me…okay, look I don't like to bother people…. I like doing my own thing…I want to be independent, so the one morning I tried injecting myself, but then the sharp point of the needle broke off in my stomach… it was a whole story (translated from Afrikaans).

Staying in control and being independent was important for Sam. She noted that her hormone therapy, unlike the cancer diagnosis was one of the few factors she was able to control. She reported that due to her personality type she experienced some obstacles, such as asking for assistance, which she had to confront while dealing with the cancer as well as the fertility preservation process.

In addition to feeling overwhelmed and scared other participants reported feeling anxious and unsure about the injection process and many relied on support from their families, friends, and partners to do this for them. Having said this, women such as Nicole, Diane, and Lisa recalled that they did not experience any challenges with the hormone therapy injections. For Diane, having to undergo the process of hormone therapy injections was “like a walk in the park”, similarly Nicole recalled maintaining her daily routine without any interruptions caused by the injections in the following interview statement:

I really found it (injections) okay...I just did the injections and carried on working…you know it did not bother me (so) much…like my husband wanted to do it for me…but I can (could) do it myself…it was really okay…(laughing) …I am not that type (of person) you know…. scared of needles.

Diane and Nicole both underwent surgical procedures before undergoing hormone therapy injections, this could possibly explain why the hormone injections were not as challenging as majority of the participants in this study recalled. For example, Nicole described the experience of the injections relative to her surgical procedure in the following interview extract:

The (surgeon) removed (my) the lymph nodes, this was very painful, I could not move my arm. It was the most painful thing ever, so these (hormone) injections were nothing compared to that.

Most women explained that hormone therapy injections were not something that would volunteer to do, but it was their only option to secure a future that includes motherhood and therefore they complied. Some women reported that they did not struggle with the injections as their previous surgery was more challenging for them. The dislike / fear of needles, the physical side effects of hormone therapy have been a noteworthy concern for participants. As a result of the various hormones injected, many participants have recalled how hormone therapy for fertility preservation affected them physically which will be explain in a later sub-theme within this theme.

During the fertility preservation several of the women noted that they focused their thoughts into the fertility preservation process, as a way of avoiding thinking about their upcoming cancer treatment. For Nicole, the fertility preservation was a way in which she could occupy her anxiety-provoking thoughts with, however once this was completed, she had no other choice but focus on the cancer treatment. Nicole stated the following with regards to her thought processes in terms of her upcoming cancer treatment:

I felt a bit sad, because that was when my chemo started, so I felt more depressed. we did what we could do and we were like happy, we got enough (eggs)....and that is what we thought, we did what we could do and like I did not have to think about it (cancer treatment) but it had to start… (shoulder shrug)

Nicole and several of the other women used fertility preservation as way of avoiding (coping mechanisms) thoughts of the cancer and their upcoming cancer treatment.

Undergoing fertility preservation was a temporary avoidance that allowed participants breathing space before embarking on the more challenging cancer treatment. Several of the women expressed that although they were able to move on after the fertility preservation and could enter the cancer treatment without any feelings of regret, they could not help but think about their total eggs harvested, the viability of the eggs and whether they would sow the efforts they put in, in the future. For example, Lisa explained that during her hormone therapy and egg harvesting she was very positive but once this was completed the "devil started playing with my head" and she experienced negative thoughts about the sustainability of the proses and whether the process was worth the money and time. In addition to Lisa, several of the other women, such as Nicole, Jolene, Jodi, Lisa, and Sam reported that they were satisfied with their fertility preservation process, however they all report having some underlying thoughts about the success of the process.

5.5.4. Pursuing fertility preservation despite the risk

Fertility preservation poses risks to women such as abnormal bleeding, infection and rarely, severe complications. Women in this study reported that they were aware of these, and some reported experiencing them. For a few participants, particularly those with hormone sensitive cancers undergoing hormone therapy was particularly risky, as conveyed by doctors. For example, Jane stated that "they (oncologist and fertility specialist) were very clear on the risks involved in putting myself in a position where I had to undergo hormone therapy". Sam and Jodi also mentioned that undergoing hormone therapy could have stimulated the growth of cancer cells other parts of their body.

Jodi explained that her awareness of the risk associated with treatment prompted her to consult with her oncologist before undergoing hormone therapy, who recommended that she undergo an ultrasound before and after treatment to ensure the cancer cells did not increase. The following interview segment reports on the concern and precaution methods Jodi took.

I can't remember if I heard this at the lab or if it was someone outside of the lab that told me that they said the hormones itself can stimulate the growth of other cancer cells, so I.. don't know how true it is...I mean everyone has their own theory about everything, but uhm as far as I concerned, I spoke to my oncologist…I did a scan, and after the scan, so you do scan before a scan before and after, so to speak, and the was no real change in terms of my cancer growth.

For women, such as Nicole, Jodi, and Sam undergoing hormone therapy may have posed a higher risk compared to the other participants who had non-hormonal related cancers. However, for those who were at risk, precautionary measures were taken to ensure that their health remained relatively safe during the procedure. Jane stated that if undergoing fertility preservation posed too much risk to her health, she would have declined. Jolene and many of the other women reported that despite knowing the risks involved, they opted for fertility preservation.

For women, such as Nicole, Diane, Jane, Lisa, and Sam, delaying cancer treatment to accommodate fertility preservation was a joint decision that their partners fully supported but not without concerns given the fact that hormone treatment and egg harvesting may pose a potential health risk. For example, in the following interview segment Nicole recalls on her husband's concerns regarding her undergoing fertility preservation:

I guess you could say that he was concerned about me and the breast cancer, cause my breast cancer is hormone sensitive.

Nicole stated that her husband was more concerned with her cancer metastasizing, whereas she was more concerned about her ability to become a mother. It is evident that participants and their partners were aware of the risks involved in pursuing fertility preservation but opted to continue regardless of these risks.

5.5.5. Physical reactions to fertility preservation

Undergoing roughly two weeks of hormone therapy as part of fertility preservation resulted in some of the participants experiencing physical changes in their bodies. Although the physical side-effects were temporary, many women felt that it was an important part of the process that should be noted. For some, like Rochelle the physical side effects of fertility preservation did not end with the gametes being removed. Rochelle reported having a negative experience the first time she underwent fertility preservation. According to Rochelle she was not informed of any or severe potential physical risks associated with the process. Rochelle described a negative experience when undergoing egg harvesting, as reflected in the following statement:

> *I started going into an immense amount of pain and like at 2 am I went into shock…from the pain. I was laying there and my whole body would go into foetal position, and I couldn't breathe or scream…it was the most awful pain I ever felt in my life… I like felt like I was having a heart attack.*

Rochelle recalled feeling frustrated and "emotionally screwed up" after the first attempt of egg harvesting. After doing her own research, Rochelle described that she may have experienced hypertension. Her body went into spontaneous spasms every 30 minutes and would last for a few seconds. Based on her research, Rochelle thought that her body went into shock from the pain she experienced. Despite this experience, Rochelle underwent a second round of fertility preservation two days later and retrieved 11 successfully frozen gametes.

Nearly all participants described feeling uncomfortable, and bloated, from the hormone therapy injections, which for some resulted in some disruptions in their daily lives. For example, Jolene recalled how hormone therapy affected her ability to engage in physical activity in the following interview extract:

Towards the end you become very bloated before they remove the eggs...like it became very uncomfortable...and during my cancer like I ran and road bicycle. Like I stayed very active...but with the hormone therapy it got really uncomfortable for me and ja I couldn't do those things anymore....it (gamete harvesting) was just more of a relief to get it over with...

For Jolene, partaking in physical activity was a way in which she could alleviate negative thoughts and distract herself from the situation which she found herself in. Similarly, Nicole stated that the only physical side effect she remembered from the hormone therapy was the experiencing feeling “bloated” but nonetheless expressed that “fertility preservation and gamete harvesting was such a happy process”.

In addition to dealing with feeling bloated and uncomfortable, a few of the women recalled experiencing pregnancy like symptoms. For example, in the following interview extract Jodi, recalled feeling physically ill during fertility preservation:

I was feeling very nauseas, threw up like once or twice, like would wake and feel like I would have morning sickness. I can imagine that is what pregnancy feels like, it was not fun....it was probably worse than the chemo even.... I could not eat or do certain things, it really felt like pregnancy.

Jodi stated that she also experienced fatigue and regarded the hormone therapy as more physically and emotionally demanding than the cancer treatment itself. Jodi recalled the physical effect that the hormone therapy had on her ability to perform even the simplest daily tasks such as walking a few meters, bathing, cleaning, and preparing a meal. Diane also recalled how the fertility preservation and IVF affected her ability to perform daily tasks.

Diane recalled that the second round of IVF and fertility preservation had a greater impact on her body physically compared to the first round.

For women, such as Lisa, Nicole and Sam no significant physical impact was reported, and they recalled feeling completely happy with the process even though they did feel “slightly full” towards the very end of the gametes being harvested. Some participants reported a temporary physical side-effect because of the hormone therapy injections, however for a few women the fertility preservation process was associated with temporary emotional side-effects.

5.5.6. Emotional vulnerability

The previous theme on the emotional responses focused reported on the emotional reactions associated with the initial cancer diagnosis, whereas this sub-theme reports on the emotional responses during fertility preservation. Several women reported that they were already emotionally volatile after receiving their cancer diagnosis and that undergoing hormone treatment exacerbated their volatile emotional status. Several of the women explained that they were happy to start with the hormone treatment to forget about their cancer, however, the daily injections were a constant reminder of their cancer. For many, such as Caroline, hormone treatment induced feelings of anger and despair around her cancer and possible infertility. Many of the women described the entire process as an emotional burden for them, whereby they articulated feelings of sadness, anxiety, confusion, hopelessness, and anger. For example, Sam, who struggled with the injections recalled that the hormone therapy affected her emotions considerably. She elaborated on her emotional status during hormone therapy in the following interview extract:

The first morning was just tears (first injection) ...you know some days were harder than others. I mean my hormones were heightened already…so I was very emotional…it was for me (participant started crying) …the whole process was just very emotional for me (translated from Afrikaans).

A few of the other participants reported similar emotional responses during hormone therapy. Many recalled going on an "emotional roller coaster" where they felt, sad, scared, and anxious about the cancer and fertility preservation. For example, in the following interview extract, Jodi expresses her awareness of the "emotional- roller coaster" she experienced during her treatment process:

I would say it (fertility preservation) was emotional… only because the, of the drugs, it takes you on an emotional-roller coaster... I would say only because of that... like cancer in general is emotional and then you add hormones to all of this, but I would not say that the hormone treatment is negative at all...It was a very positive thing for me

For most of the women cancer was emotionally demanding and by injecting hormones created a temporary whirlwind of spontaneous emotions which many did not recognize at the time. For example, Zandre, a 25-year-old female who described herself as being strong-willed and in control of her emotional reactions noted that whilst she was on the hormone treatment she would spontaneously start crying.

However, two of the women noted that they did not experience intense or out of the ordinary emotions during their fertility preservation process. These participants stated that their resilience and emotional stability could be because of their “strong-minded” (Jolene) personality or believed that for them it was “mind over matter” (Caroline). For some women, such as Nicole and Jolene the concept of psychological resilience served as a coping mechanism strategy to control their emotions and feelings. For example, Jolene, explained the following in terms of the fertility preservation and her thoughts and emotions around the process:

I must say I did not really experience that (crying)...because...always being like a very strong-minded person so I was able to control myself...and... situations like that...uhm and ja I just had to control myself. I didn’t want to get stuck in that… (negative mindset)

As indicated above the process of undergoing fertility preservation required the women to challenge their sense of self-control and employ various coping mechanisms to manage emotionally and psychologically. Women from this study noted that the fertility preservation process was at times an emotional experience that they found themselves in and one had to fight against. In addition, for some women the hormone therapy was a constant reminder of the situation they were in. For two women hormone therapy was associated with pregnant like symptoms while facing the possibility of infertility.

5.5.7. Social interactions during fertility preservation

Several of the women stated that they withdrew socially from family and friends because during fertility preservation and attributed this to the emotional and physical toll that treatment placed on them. Women cited feeling physically ill (nausea, vomiting, fatigue, and bodily pain such as blue marks on their stomachs), and experiencing emotional exhaustion (crying, anger, confused, hopelessness, sadness, and experiencing depressed like symptoms) as the cause of their social withdrawal. Fortunately, most of the women from this study reported that they had support from family and friends, and many relied on their partners for support. Jane acknowledged that during her fertility preservation process her husband became the sole person whom she relied on, "he was like my friend, father, and my husband". She acknowledged that she was not a very sociable person and withdrew socially even more fertility preservation.

The women from this study noted that they made a conscious decision to socially withdraw themselves from family and friends as soon as they received their cancer diagnosis. For example, Caroline stated that she did not want people to feel sorry for her because of her cancer, thus she did not really tell anyone about her diagnosis. For a few participants, the decision to socially withdraw themselves only became a realization once they were in the fertility preservation process and having to deal with the physical and emotional side effects as mentioned above. For example, Jodi explained that her emotional status and physical state often influenced her socially. She coveys this message in the following interview extract:

Uhm... I was obviously just very emotional with the hormone treatment so, I did not really go out, because…uhm...I, felt like I am you know wanted to cry all the time and then I was physically just tired and uncomfortable… that is just, I guess the hormone that they pump in...

For Jane, being a "home body and in my own social bubble" during the time of her fertility preservation process served as a coping mechanism whereby she could process the cancer diagnosis and the fertility preservation in her own time and environment without the input of other individuals.

The physical and emotional toll of fertility preservation resulted in social withdrawal for many participants. Other factors such as having cancer also contributed to social withdrawal. Diane verbalised that the entire process of undergoing fertility preservation, shortly after dealing with her partners' cancer, created some sense of isolation, and she started feeling withdrawn and depressed. Diane explained that she and her husband were always anticipating that something negative would happen that they even kept their pregnancy a secret from some of their friends.

It is evident that participants experienced physical, emotional, and social consequences as a result of their fertility preservation. In the next section I report on how they coped.

5.6 Thoughts processes and coping skills during the fertility preservation experience.

Before describing participants' coping strategies, I will briefly describe the thought responses participants reported before, during and after their fertility preservation procedures, as this provides the context in which various coping skills were applied. During the interviews women described that they usually employed various coping skills at times unconsciously, to accommodate and alleviate negative thoughts they experienced. The first three sub-themes collectively focus on the thought responses relating to the fertility preservation process, whilst the last sub-theme will focus largely on the coping skills used during the fertility preservation process. During the initial interviews it became evident that all the women experienced a variety of thoughts ranging from positive to negative before, during and after their fertility preservation treatment.

5.6.1. All about the eggs

Women in this study reported that the opportunity to undergo fertility preservation to preserve biological motherhood provided them with a sense of promise, promise in a life after cancer, survival, and biological motherhood. Several women in this study reported their initial thoughts after their cancer diagnosis and before undergoing fertility preservation. For many, the opportunity to undergo fertility preservation provided a glimmer of hope at a time when they may have felt confused, anxious, scared, and angry. However, this was not without significant financial cost. For example, Nicole reported the following thoughts before undergoing fertility preservation:

The worse part was that I could not have another child and you know that problem was probably solved...that was a big thing that came off my shoulder...I just thought that I something to look forward you know, but like I was still a bit scared you know, and it is not a cheap process.

As the statement from Nicole suggests, fertility preservation gave her something to look forward to, in other words, a sense of promise. Several of the women such as Jodi, regarded the process as “uncertain” since there is no “guarantee” in undergoing fertility preservation. For Jodi and several of the other participants in this study the uncertainty around total of gametes harvested, quality of the gametes and survival rates of the gametes were on their minds prior to the fertility preservation. Many expressed having some doubts about hormone treatment and oocyte harvesting prior to the process and whether the process would be successful at all but still saw promise in the process. For example, Rochelle shared her thoughts in the following interview segment regarding her thought process prior to fertility preservation:

> *I had a lot on my mind, like fact that I would not be able to have my own children or well that there was a possibility you know that I could die… but I was also very excited that I had that option because I didn't know there was that…I can still , like it can and will still be my biological child…but you know and its very expensive for a chance at this (fertility preservation).*

For Rochelle, the uncertainty about the future of her own health was a central consideration before undergoing fertility preservation, but she felt excited about the promise that fertility preservation presented her with. The next sub-theme focusses on the importance of the total eggs harvested.

5.6.2. Counting eggs

Women expressed the thoughts that they had during the hormone treatment and fertility preservation were largely focused on the hopes of harvesting sufficient gametes. For many this would have meant that fertility preservation and all the factors associated with it, was worth it despite overcoming and dealing with several challenges. Several of the women noted that they only had one opportunity to undergo fertility preservation due to various time (medical and biological) constraints. For example. Nicole, who had been diagnosed with a hormone sensitive breast cancer noted that she only had one opportunity to undergo fertility preservation. In the following interview segment Nicole recalls on her thoughts during the hormone treatment and gamete harvesting process:

> *I hope that I get (enough) eggs (laughing).... that it is worthwhile, at least if I get some eggs, I had some chance you know. I did what I could and that was it you know... I had 15 eggs! I was so very happy you know. The nurses were all like wow, 15…they were happy for me but after that I was a bit sad you (be)cause that is when my chemotherapy started.*

For several like Nicole being over the age of 30 years old at the time of their egg harvesting and producing enough gametes were described as "pure luck" and a "miracle" by some her and some several other women who had experienced the same. Nicole noted that she and the nurses were shocked at the number of gametes they managed to harvest, taking her age at the time of fertility preservation into consideration. Similarly, Jolene noted that during her fertility preservation process her thoughts were like those of Nicole. Jolene commented the following with regards to her thoughts and expectations of fertility preservation during the entire process of hormone treatment and egg harvesting:

Ja not really like that concerned about it (fertility preservation) ...but more like if the process was going to be successful. It is like I almost only had one shot... because I wanted to start my treatment ASAP in the fear of it spreading ...so but ja...ugh I just took it as it came.

Jolene noted that during her fertility treatment she did not have any major concerns about the medical process, however she was concerned about the outcome of the egg harvesting and whether this would be successful or not. For women, like, Nicole, Jolene, Jane, and Diane having undergone fertility preservation and having sufficient gametes harvested reduced all concerning thoughts they may have had prior to undergoing fertility preservation. For example, in the following interview segment Diane recollects the thoughts she experienced during her fertility preservation:

Oh for me...let's see...uhm I was at peace about it, and I just kept thinking we had fought the cancer… and I just had some peace about it (fertility preservation) uhm...I was angry obviously because what had happened to John again (cancer reoccurrence), so very angry...but I think I was at peace knowing that there was something we could you know to complete the last part of the circle.

Diane was relieved that doctors managed to retrieve sufficient gametes the second time of fertility preservation. Rochelle, who had an exceptionally negative experience and who harvested very little gametes during her initial round of fertility preservation commented the following with regards to her thought processes during the first and second attempt of fertility preservation:

Uhm the first time was a lot of fear, like I my thoughts were just around like fear I had but I was not entirely sure about what specifically...but I am sure the needles had to do with it or if it was because I still had to do the chemotherapy, that did bring a lot of fear into my head…the second time (fertility preservation) was the actual fear of the process…I don't think I had actual fear of the process but more like the needles and chemo(therapy) the first time but as result of what happened I had a lot of fear and anger the second time you know.

Rochelle noted that her thoughts changed between the first and second attempt. During the first attempt she was more concerned about the hormone injections and her upcoming chemotherapy, whereas during the second attempt she was more concerned about the process and harvesting sufficient gametes.

Both Diane, and Rochelle indicated that their thoughts also shifted from the first attempt and the second attempt of fertility preservation. Diane was less angry towards her situation and expressed that she “really enjoyed and embraced” the second fertility preservation attempt. Rochelle, on the other hand explained that going into the second round of fertility preservation her fear of needles had decreased and the hormone treatment was not much of a concern anymore, but more so the actual process of egg harvesting. Nearly all the women, apart from two (Diane and Rochelle), managed to produce and have sufficient gametes harvested, thus their hope during fertility preservation successfully achieved.

Although all the women, apart from the above mentioned two managed to produce and harvest sufficient gametes some of them, some still expressed disappointed with their number of eggs that they had harvested and preserved. For example, Caroline, a 30-year-old woman expressed her thoughts with regards to the fertility preservation process in the following interview extract:

I was heartbroken and let down at the fact that I only had four eggs….and for the longest time it was only until recently I had like this sense of I can never have my own kids…and all of this was for nothing…I think like it was only within the last month or two that I had a revelation of knowing that I am going to have my own children uh…I mean it only takes one egg.

For Caroline, having only four eggs harvested was quite disappointing and heart-breaking. At the time of the interview Caroline expressed that she only recently dealt the disappointed and shared optimism about her preserved oocytes. For many women, such as Jane, Caroline, and Jolene, actively compartmentalizing everything served as a way in which they could cope with thoughts and situations that were too overwhelming to process.

5.6.3. Focus on eggs

It is evident in the interview extracts that once the women had their eggs and did what they felt they could to protect their future fertility they were able to focus on the cancer treatment. Women reflected on their thought processes after they underwent fertility preservation. For several of the women the end of the gamete harvesting process resulted in thoughts of relief, satisfaction, and confidence, while a few women reported that they were left feeling disappointed, heartbroken, and fearful about their upcoming cancer treatment and their preserved gametes. Either way, participants reported acceptance, for example, Nicole noted the following with regards to her thoughts and feelings after the egg harvesting procedure:

We were relieved that, it was done, and they were going to freeze it and we had faith in [fertility specialist], that it would all go well. And then it was only chemo and radiation and everything that go(es) with this [cancer]….

Nicole and several of the other women who had harvested sufficient gametes expressed feeling relieved and content about their future that may very well include biological motherhood as most of them had enough gametes for several attempts. However, several of the women who did not manage to harvest as many gametes as they would have liked to express having negative thoughts regarding the process. For example, in the following interview segment Caroline voiced her thoughts about the egg harvesting and upcoming cancer treatment:

I was a bit angry but also like I have dealt with a lot of grieve in my life so I knew how to push it down , well sort of mask it for as long as I can just to get out of that thing, so after the fertility treatment my focus was on going and surviving the chemo and coming out on the other side, I have not even really stopped to much to think back about everything I have gone through, like with the eggs and that whole process.

For Caroline, only having retrieved four eggs, meant that her thoughts after fertility preservation were concerned around that the fact that she did not manage to harvest enough gametes. For her the process after the egg harvesting was one that was associated with grief and disappointment. To cope with these anxiety provoking thoughts the participant decided to accept the outcome and instead focus on the chemotherapy and surviving cancer. Similarly, Zandre, noted that she was somewhat disappointed with her seven gametes that were harvested as she was expecting to harvest much more but accepted the outcome as she did not have enough time to undergo the process again.

For several women, fertility preservation was a happy experience and the process ended on a high note with them having harvested numerous eggs. However, their high spirits were brought down promptly with the harsh reality of having to undergo cancer treatment which was considered more challenging.

5.7 Conclusion

In this chapter I provided contextual information on the emotional reactions to the cancer diagnosis and the subjective experience of fertility preservation. I found that cancer was a life-altering event that was unexpected for some women, disruptive and seen as an invasion of their lives. Shock, anxiety, anger, and depression-like symptoms were common emotional reactions to the initial diagnosis. Furthermore, all the women in this study valued the importance of motherhood and opted for fertility perseveration, even if this meant risking their cancer metastasising. Moreover, a large section of this chapter reported on the subjective experience of fertility preservation, during the analysis five subthemes and ten sub-themes were developed that collectively expose the fertility preservation process. In the next chapter I will provide a discussion on the results while integrating the theoretical framework used in this study.

Chapter 6: Discussion

6.1 Introduction

The primary aim of this study was to explore the subjective experience of fertility preservation among cancer survivors. Although research on fertility preservation has increased globally, there remains a shortage on the subjective experiences of fertility preservation, particularly within the South Africa context. The following chapter provides a summary of the five key themes developed in this study and discusses these findings within the broader research corpus as outlined in chapter three and my chosen theoretical framework, the health belief model.

6.2 Discussion of findings

6.2.1. A cancer diagnosis: dealing with emotions

The first theme derived from the interviews and data analysis described participants' emotional reactions to their cancer diagnosis. In line with previous research (Cjulay, 2013; Guenther et al., 2012; Warren et al., 2018; Williams & Jeanetta, 2016), women reported that a diagnosis of cancer was unexpected and disheartening and disrupted all areas of their personal, social, and marital lives. Cancer was perceived as an invasion in their lives that initiated feelings such as anxiety, anger, and depression-like symptoms, all reported in other studies among women with cancer (Clay, 2013; Guenther et al., 2012; Kagee et al., 2018; Smit et al., 2019; Williams & Jeanetta, 2016c).

The psychological distress reported by the women in this study reflected findings from previous research (Clay, 2013; Guenther et al., 2012; Oborn, 2014; Williams & Jeanetta, 2016d), which suggested that psychological distress is often experienced at initial diagnosis. The women from my study reported that they started eating healthier and maintained physical activity, if they were able to, to assist them with coping while attempting to avoid the cancer metastasizing. This is in contrast with (Zhu et al., 2017) who reported that in their study, women who had advanced stages and aggressive cancer displayed high levels of mood, substance abuse and anxiety disorders. (Zhu et al., 2017) state that due to the intense psychological distress experienced, women were less likely to engage in physical and social activities. Moreover, the researchers reported that these women found it challenging to adjust and cope with their cancer diagnosis.

Despite a substantial proportion of cancer patients suffering from emotional disturbances, studies have consistently shown that the lack or absence of a clinical disorder among cancer patients is more common than expected (Santre et al., 2014). It is possible that primary health care providers fail to identify clinically significant anxiety and depression in cancer patients, as it is reflected in the study by (Kagee et al., 2018; Santre et al., 2014) who depicted that the prevalence of emotional distress as being specific to the circumstances and therefore this is often overlooked. The women in my study presented with aggressive and advanced stages of cancers, however, none of the women reported being diagnosed with any mood, anxiety, or substance abuse disorder. Many of them reported symptoms relating to depressive and anxiety mood disorders during their cancer treatment, but no clinical diagnosis was sought or given.

6.2.2. Fertility preservation: A chosen biological investment

In the second theme, women reflected on the choice they had to make between receiving immediate cancer treatment or delaying treatment to accommodate fertility preservation. All the participants in this study chose to delay their cancer treatment to accommodate fertility preservation. The decision of whether to delay cancer treatment to accommodate fertility preservation is highly complex for newly diagnosed female cancer patients, especially for those who are in their reproductive years (Quinn et al., 2010). Women in my study reported that the decision to undergo fertility preservation before undergoing cancer treatment was easy for them, despite being under a great deal of psychological distress at the time. (Melo et al., 2018) the decision to undergoing fertility preservation is usually made under high levels of psychological distress since patients need to simultaneously deal with their recent cancer diagnosis and upcoming cancer treatment. Research by (Ehrbar et al., 2016) among 12 female oncofertility patients from Switzerland, indicated high willingness from participants to delay cancer treatment despite severe and life-threating consequences to accommodate fertility preservation.

Consistent with my findings, women reported that despite the negative aspects of fertility preservation such as lack of information, time constraints, financial implications and potential risks involved; positive aspects such as securing their future fertility outweighed all negative aspects (Ehrbar et al., 2016). Observations from my study showed that factors such as potential risks, costs involved, and type and stage of cancer were considered by participants during their decision-making process. However, the desire for motherhood outweighed the consequences of risks associated with delay in treatment. In contrast with my findings, many participants in other studies reported that they were not willing to delay cancer treatment and the uptake in fertility preservation was low because of the potential risks and financial implications associated with fertility preservation (Hershberger et al., 2016; Parton et al., 2019c). However, this difference can be attributed to inclusion criteria differences, whereby I only interviewed participants who opted for fertility preservation.

Another contrasting finding relating to religious and ethical reservations was observed among participants in other oncofertility research. Drawing data from 46 Australian women, (Jones et al., 2017a) reported that women who were exceptionally religious, believed that fertility preservation was not a natural manner to conceive. However, women from my study did not report any religious reservations or conflict, instead religion was used as a coping strategy. Furthermore, participants in two other studies from Portugal and Switzerland (Ehrbar et al., 2016; Melo et al., 2018) indicated that the decision-making process was one that was complex and ethically demanding which contrasted with the findings of my study. Women in the current study reported that they gave the decision some thought but it was not a difficult decision to make in terms of their religious or ethical beliefs, values, or morals.

6.2.3. Importance of motherhood

The third theme, namely the importance of motherhood focused on the desire for biological motherhood. Research has shown that motherhood remains a highly valued goal for many women, a goal that is threatened when they are diagnosed with cancer (Boz et al., 2018; Croson & Keim-Malpass, 2016; Maher & Saugeres, 2007). Similar to my findings, (Hershberger et al., 2016) found that women who accepted fertility preservation reported a strong desire for biological motherhood, which for many formed as basis for their identity building (Alamin et al., 2020). (Hershberger et al., 2017) reported that for those who declined fertility preservation, importance was placed on surviving cancer and not on motherhood. One reason for this could be that women who declined fertility preservation did not place significant importance on becoming a mother or had already achieved biological motherhood before cancer diagnosis. This contradicts feedback from two of the participants in this study, who despite already having a child at the time of the interview, their desire for (more) children was not any different to that of a woman without any children.

6.2.4. Understanding fertility preservation

The fourth theme described the experience of fertility preservation. Seven sub-themes were developed that give a combined overview of fertility preservation. Namely, certainties and uncertainties: embarking on the process, importance of access to knowledge, facing their fears: fortitude in the face of hormone treatment, fertility preservation: potential risks involved, physical reactions to fertility preservation, emotional vulnerability, social interactions during fertility preservation. Participants from this study reported that embarking on the fertility preservation process was undertaken under several certainties (importance of motherhood) and uncertainties (potential risks and costs involved). (Komatsu et al., 2018b) study confirm participants experiences of several uncertainties, such as limited knowledge and time, effectiveness of fertility preservation, future fertility status, potential risks involved and their own mortality. This corresponds with the outcomes of the (Parton et al., 2019a) study which found that women embarked on the process of fertility preservation with certainties and uncertainties over the preserved material (eggs) and future fertility outcomes. Despite the uncertainties women reported having, preserving biological material before cancer treatment was constructed as hope and insurance (Parton et al., 2019c).

Similarly, women in this study acknowledged that they were willing to risk delaying cancer treatment to accommodate fertility preservation, yet many reported that this was not without concerns. Nonetheless, all of them reported feeling pleased at the opportunity to actively partake in the process despite the absence of guarantees.

Women in the current study acknowledged that embarking on the fertility preservation process within two weeks after receiving their initial diagnosis caused anxiety and fear. Women who reported high levels of anxiety and fear attributed this to lack of background information about the process of fertility preservation. Lack of knowledge and familiarity with fertility preservation are listed by (Daly et al., 2019) as the major contributing factors to the discomfort, fear, and anxiety women experience before commencing with fertility preservation. This demonstrates, that while women report having hope and appreciation for fertility preservation the process is not without initial psychological distress (Daly et al., 2019; Jones et al., 2017a).

Trust in doctors as reported by participants in the current study played an important role in the process of fertility preservation. Women from this study stated that they trusted their fertility specialist and followed all protocols as advised by fertility and oncological specialists. This may be due to the support women received from the fertility and oncological specialists they interacted with. Despite having limited time and knowledge women reported feeling emotionally, physically, and informationally supported which they reported decreased levels of anxiety and fear. Support from health care professionals served as a buffer against psychological distress associated with undergoing fertility preservation in other research too (Mai, 2008).

Consistent with reports from women in other studies (Hammarberg, 2001; Matsota et al., 2015; Pinelli & Basile, 2018; Rodriguez-Wallberg & Oktay, 2014), women from my study reported experiencing mild to moderate emotional and physical side effects during fertility preservation. This included experiencing premenopausal and pregnancy-like symptoms, such as feeling fatigue, uncomfortable, bloated, sweating, bruising, nausea, and hypertension. Women reported that experiencing symptoms normally associated with pregnancy caused psychological distress as this was a constant reminder of their situation. Female participants in this study confirmed that there was no single unified experience of fertility preservation for each person. Rather, the experience of fertility preservation (hormone treatment and gamete harvesting) comprised of a variety of pleasant and unpleasant experiences, as also indicated in other studies (De Vos et al., 2014; Jones et al., 2017a).

Consistent with the current literature on fertility preservation (Martin, 2010a; McLaren & Bates, 2012b; Thompson, 2013; Tschudin & Bitzer, 2009; Vitale et al., 2018a), the participants in this study that their fertility preservation process was an emotional-roller coaster with a few reporting moderate physical side effects, such as fatigue and nausea. According to (Martin, 2010b), experiencing an emotional roller coaster could be recognized as imbalance of hormones due to hormone treatment received. Furthermore, participants from (Inhorn et al., 2017) study and the participants from this study stated that despite feeling physically and emotionally volatile, the opportunity to undergo fertility preservation to secure a future that included motherhood was viewed as a sense of accomplishment.

Participants from the current study stated that the fertility preservation process prepared them for their upcoming cancer treatment that commenced a few days after their oocyte retrieval. For example, several women reported a strong dislike for needles before undergoing hormone treatment, despite fearing the multiple, daily injections required with hormone treatment they were still willing to complete their treatment and their fears were reduced when they commenced with their chemotherapy. (Pedro & Mwaba, 2013) echoed these findings, women from their study completed their hormone treatment in preparation for in-vitro fertilisation and embryo transfer, despite having a dislike for needles, indicating the measures women are willing to undergo to achieve pregnancy. Consistent with previous research conducted in Switzerland, Chicago, and Japan (Ehrbar et al., 2016; Hershberger et al., 2017; Komatsu et al., 2018c), the experience of fertility preservation varied among the participants, however, nearly all the women in this study shared similar thoughts and concerns relating to their hormone treatment, oocyte harvesting and cancer treatment.

In the fifth theme, female participants described their thoughts and coping before, during and after fertility preservation experience. The theme consists of three sub-themes namely, all about the eggs, counting eggs, and focus on eggs. In the first sub-theme, women shared their thoughts before undergoing fertility preservation whereby all the women had a sense of hope and promise about the fertility preservation process as well as their potential future fertility status. This corresponds with the findings by (Parton et al., 2019a), among 61 women from Australia who reported that fertility preservation resulted in hope regarding the possibility of motherhood beyond cancer. Furthermore, participants in another study reported that they considered their stored fertility (oocytes/embryos) as “frozen hope”, despite there being no guarantees in the process (Quinn et al., 2010) which was also reported by women in the current study.

In the second sub-theme women reflected on the anticipation and concerns about their fertility preservation process, such as harvesting enough gametes, financial implications, and success rates after cancer treatment. During the fertility preservation process many participants recalled feeling anxious and confused at first. Several participants attributed their emotional responses to their lack of or absence of sufficient knowledge about fertility preservation. However, their emotional distress shifted overwhelmingly to that of more positivity once the egg harvesting procedure was completed successfully and they could move onto the next process as reported by participants in other studies (Dyer & Quinn, 2016; Jones et al., 2017a).

For many women this meant that they could commence with their cancer treatment knowing that they did everything that they could to secure biological motherhood in the future (Parton et al., 2019a). The expectation to harvest sufficient gametes was heightened among the women in my study as many reported only having one opportunity to delay cancer treatment to undergo fertility preservation. This corresponds with the outcomes of (Jones et al., 2020), study, which found that women had high expectations to produce and harvest sufficient gametes since they were under extreme time constraints.

The third sub-theme reflects the participants thoughts once they had completed their fertility preservation process and focused on their gametes that were harvested. In line with previous research (Batool & de Visser, 2016b; Hasanpoor-Azghdy et al., 2014), participants from this study stated that during their fertility preservation process was exclusively focused on securing a future that included biological motherhood. For some, undertaking fertility preservation was a distraction from their cancer diagnosis, however, reality of their upcoming cancer treatment was unavoidable. For a few women, the ability to start their cancer treatment was welcomed with the hopes of treating the cancer as soon as possible so that they can start on expanding their family.

6.3 Conceptualizing the health belief model using the findings

As described in Chapter 3, according to the heath belief model, people will undertake certain actions to prevent an illness/condition if they regard themselves susceptible to the condition, perceived that the condition would have severe consequences, perceived that undertaking a certain action will be beneficial and if they perceive few barriers exist that will prevent them from undertaking a certain action (Rosenstock, 1974). Additionally, the model suggests that specific cues to actions, such as external and internal factors in one’s personal (experiencing internal symptoms) or social environment (advice from family, friends, and health care professionals) can impact the final action taken (Champion & Skinner, 2008).

Even though the health belief model has been used to describe a range of health seeking behaviours, it has not often been used previously as a framework for research to assist with understanding the uptake of fertility preservation among cancer survivors (Gorman et al., 2020). However, recent researchers have determined that the health belief model is suitable to predict the decision to undertake fertility preservation (Sousa-Leite et al., 2019). It is believed that the intention to embark on the process of fertility preservation depend on the perceived barriers and benefits of undergoing fertility preservation, perceived susceptibility, and severity to infertility, as well as certain cues to action that may prompt women to consider fertility preservation. In this section of the discussion, I will position the themes according to the six constructs as per the health belief model.

Although the health belief model has previously referred to perceived susceptivity and severity as two individual constructs (Rosenstock, 1974), recent studies have argued that perceived susceptibility and severity may combine to form a single construct, which they refer to as perceived threat (Champion & Skinner, 2008). In the present study women reported that when they received their diagnosis and were made aware of the potential loss of their fertility, their first instinct was to consider their future fertility and the importance of biological motherhood. Women reported that cancer, more specifically cancer treatment and facing infertility because of cancer treatment regimens was considered a threat to their motherhood. Both (Sousa-Leite et al., 2019; Ter Keurst et al., 2016) reported that the intention to undergo fertility preservation was prompted by the perceived susceptibility of experiencing infertility and how severe the consequences of infertility would be. To add to this, (Gorman et al., 2020) found that for women potential infertility would be emotionally difficult and unbearable, and they could not imagine accepting infertility. Moreover, it is possible, though not definite that despite accepting perceived susceptibility to infertility, the perceived severity thereof is so significant for women, that they would pursue fertility preservation despite the financial and health implications.

Perceived benefits refer to an individual’s assessment of the internal and external value or importance of engaging in health seeking behaviour (Washburn, 2014). Individuals believe that undertaking an action will decrease the susceptibility and severity of the disease regardless of effectiveness of action (Renu et al., 2015). The most significant perceived benefit associated with undergoing fertility preservation prior to undergoing cancer treatment are ensuring one’s future fertility by harvesting sufficient gametes during hormone treatment (Gorman et al., 2020).

Women in this study reported that by undergoing two weeks of hormone treatment and subsequently enduring oocyte retrieval, they could ensure a future that included biological childbearing opportunities. Even though the women in my study reported that there were no guarantees in undertaking fertility preservation, the notion or the sense of future biological motherhood was a significant beneficial construct during the decision-making process in this study, which for all alleviated a significant amount of stress while providing a sense relieve. Women in this study reported that while the decision to delay cancer treatment to accommodate for fertility preservation, was an easy decision, done without any hesitation, it was not without several perceived potential barriers.

According to the health belief model, perceived barriers refer to an individual’s perception of obstacles that may hinder behaviour change (Renu et al., 2015). Consistent with commonly cited barriers in the uptake of fertility preservation, (Gorman et al., 2020), stipulated that the financial and health implications were found as contributing factors in the decline of fertility preservation. Women from my study reported that during the decision-making process, they had to consider several factors, such as the potential health and financial risks involved in undertaking fertility preservation.

A few women from my study reported that if undertaking hormone treatment as part of the fertility preservation could have potential negatively affected their heath, they would have declined. Therefore, consistent with previous studies (Gorman et al., 2020), significant barriers in the uptake of fertility preservation could be the negative and potentially harmful physical side-effects of hormone treatment, such as their cancer metastasizing.

While most women were able to fund the fertility preservation process form their savings, many had to find alternative financial funding from employers and family members. It must be noted that all participants underwent fertility preservation, and it may be more informative to interview women who did not undergo fertility preservation prior to cancer treatment to gain a detailed understanding of the barriers.

Cues to action refer may refer to internal and external factors that assist individuals in making health-seeking related decisions (Renu et al., 2015). Women from my study stated that external advice and recommendations from their oncologists in conjunction with their internal need for motherhood was the trigger needed to undergo fertility preservation prior to undergoing cancer treatment. More than half of the women in my study reported that they were not aware of the potential loss in their fertility due to cancer treatment regimes, fortunately they were informed about potential fertility loss through their clinicians, and they could act immediately. Moreover, several of the women reported that support and advice from family and friends supported them during the decision-making process. (Gorman et al., 2020) echoed these findings whereby support, advice and recommendations from friends, family and doctors were associated with higher fertility preservation uptake.

Much like cues to action, self-efficacy has not been systematically assessed as a construct of the health belief model (Champion & Skinner, 2008). The health belief model states that while perceived susceptibility, severity, benefits, barriers, and cues to action collectively contribute to the decision-making process to undertake fertility preservation or not (Gorman et al., 2020; Sousa-Leite et al., 2019; Ter Keurst et al., 2016), self-efficacy has been an important but missed construct among female cancer survivors. According to (Washburn, 2014), self-efficacy is the confidence and belief that one could undertake action or to perform a health-seeking behaviour.

Women from my study reported that they did not consider their ability to undertake fertility preservation and subsequently undergoing cancer treatment, for many it was “a feat that required strong mindedness. Having said this, at the time of the interview all the women reported that they were shocked and amazed at their ability, determination, and inner strength that despite facing a variety of barriers they managed to overcome these and complete both treatments.

6.4 Conclusion

Women from this study acknowledged that while they were shocked, disappointed, angry, confused, and fearful when they received their initial diagnosis this was only temporary. These responses soon became less important when they were informed about the possible loss of their fertility due to cancer treatment regimes, thus a decision had to be made regarding their future fertility. Women stated that they had to decide if they were willing to take a risk and delay cancer treatment to accommodate fertility preservation to secure their fertility. Undergoing fertility preservation prior to undergoing cancer treatment meant that women had to endure two weeks of hormone treatment and oocyte harvesting. The fertility preservation process compromised of multidimensional positive and negative experiences for all the women. Despite facing a life-threating disease the women reported that the process has produced a feeling of being stronger and empowered, while appreciating and living life to the fullest. In this chapter, I have located my findings within the broader research corpus and theoretical framework.

Chapter 7: Conclusion, Limitations and Recommendations

The main purpose of this study was to explore the subjective experience of fertility preservation among female cancer survivors who sought fertility preservation treatment in South Africa. In this chapter I discuss the five objectives of the study and whether the findings meet these objectives. Following this, I provide a section on the limitations I encountered during the study. I conclude the chapter by outlining recommendations for research and clinical practice relating to fertility preservation.

7.1 Conclusion

At the start of the study five objectives were developed to give an understanding of the subjective experience of fertility preservation among female cancer survivors. The semi-structured interview schedule for this study was developed using the constructs of the health belief model and the research objectives. As the findings were previously discussed in Chapters 5 and 6, this section will focus on concluding the study to address the main aim and the individual objectives of this study.

7.1.1. Exploring the factors during the decision-making process

The first objective of the study was to explore and understand the factors that played a role during the decision-making process. Participants reported that they had very limited time available to consider all factors associated with the fertility process and many ended up following orders from clinicians. In addition to the time constraint many expressed, limited or lack of knowledge was associated with feeling confused and anxious about what could be expected during the process. As such, many participants reported feeling “zombie” or “robot-like” during the process. Many used this avoidant behaviour as a coping mechanism to prevent thinking of feeling intense and overwhelming thoughts and emotions relating to their cancer diagnosis.

Although the participants stated that the decision to undertake fertility preservation was made without any hesitation, they had to consider several factors. Majority of the participants acknowledged that the costs to undergo fertility preservation is significantly high. However, the costs involved would not have prevented them from undergoing and seeking fertility preservation to secure a future that included biological motherhood. Women who had been diagnosed with hormone sensitive breast cancers reported thinking about the effect's hormone treatment could potentially have on their already aggressive and advance cancer. Despite the financial and health implications fertility preservation posed, women reported that the desire for motherhood was of utmost importance.

7.1.2. Exploring the cancer and fertility preservation process

The second objective of this study was to explore the process of fertility preservation among female oncology patients. Women from this study reported that their initial responses to their cancer diagnosis included shock, disappointment, fear, anxiety, and anger. Furthermore, the women stated that they commenced with their fertility preservation process shortly after their diagnosis. Although they were still trying to process their responses towards their cancer diagnosis, they could not help but feel relieved and excited.

Embarking on the fertility preservation was met with a variety of complex feelings, such as anxiety, confusion, fear, optimism, hope and excitement. Women reported that the negative feelings associated with embarking of the process was for the most part were related to their lack of knowledge of fertility preservation and the sense of urgency associated with the process. Most of the women reported that they had limited knowledge on the fertility preservation process, hormone treatment, oocyte retrieval, and the potential risks involved in delaying cancer treatment. However, the women reported their desire for biological motherhood outweighed the limited knowledge and concerns they had about the process. While more than half reported having limited knowledge about fertility preservation, they felt that their oncologists and fertility specialists were supportive and provided sufficient information during the process. Despite facing a life-threating disease and undergoing fertility preservation, a process which was unknown to many, they managed to overcome health, physical, emotional, and financial obstacles.

7.1.3. Exploring the emotional and physical experiences of fertility preservation

The third and fourth objectives developed in this study were to explore the physical and emotional experiences of undergoing fertility preservation among female cancer patients. Participants reported that during the two weeks of hormone treatment in preparation for the oocyte harvesting, they experienced a variety of different levels of emotional, physical, and social side- effects. Women reported that they felt like crying on certain days, particularly when it came to doing the daily hormone injections, which for many was an unpleasant experience.

For many women, the daily injections were a constant reminder of their cancer and the reason why they were having to undergo fertility preservation. Nonetheless, a handful of women stated that due to unexpected news of their cancer and the imbalance in their hormones, they may have been emotionally volatile, more than they were usually. Three women reported that they felt and looked “pregnant” during their hormone treatment, especially just before their oocyte harvesting. Most of the women reported that physically, the fertility preservation process was much easier than they had anticipated before commencing with the process. Most of the women reported experiencing only some bruising around their stomach area, feeling bloated and uncomfortable.

The participants reported that due to their emotionally volatile status in conjunction with their physical side effects (such as feeling fatigue, bloated and uncomfortable) many reported that they could not resume their daily physical activities (such as running or going to the gym) and/or socially withdrew for a few weeks to process their feelings. Despite, all the temporary side-effects nearly all the women reported a general positive experience with fertility preservation.

7.1.4. To explore fertility-related thoughts and concerns

The fifth objective of this study was to explore fertility related thoughts and concerns women of reproductive age shared when they received a cancer diagnosis and faced potentially losing their childbearing abilities. Women in this study reported that they were not aware of the potential risks involved in undergoing cancer treatment, particularly the loss of their fertility. More than of half of the women reported that they were not concerned about their cancer or undergoing cancer treatment immediately, but more concerned about their future fertility, as they valued their potential for motherhood.

For a few women, biological motherhood was their only option to achieving parenthood as other alternatives such as adoption was not regarded as an option for them, due to personal reasons. Several women reported that they grew up fantasying about their future biological motherhood; this fantasizing became a construct under which they constructed their identity as a woman. However, by having the opportunity of childbearing removed due to cancer treatment and not achieving this identity they had built since they can remember, would have left them heartbroken. Essentially, some women reported that their envisioned identity as a woman and a mother would have been damaged or lost as of a result of their infertility.

A few women, including those who harvested few oocytes, reported that despite the sense of relieve they felt from what they regarded as insurance/ alternative options (preserved oocytes/embryos), they continued to feel concerned about their preserved materials. Despite being optimistic about the process and success rates, nearly all the women reported that they hoped that their preserved material would survive being preserved and thawed and that they would achieve pregnancy.

Participants reported that before undergoing hormone treatment as part of the fertility preservation process, they experienced concerns about the process, fuelled by their lack of knowledge, fear of the cancer growing due to hormone treatment agents, and time constraints. Despite the concerns about the fertility preservation process, the process offered women a glimmer of hope that in the future they would be able to engage in biological motherhood. The hope and promise fertility preservation offered for future motherhood relieved significant stress for the women. Therefore, if they were infertile after cancer treatment, it was foreseen that infertility would not have been psychologically detrimental to the women as they had their preserved material (frozen eggs). Participants reported that during the process they experienced some concerns relating to oocyte harvesting, such as harvesting sufficient oocytes, as this would have meant that the process was worth the time, effort, and money.

Most of the participants reported that the end of the fertility preservation was welcomed in that they had sufficient gametes and they could commence with their cancer treatment and start with expanding their family. However, a few women reported that they were unhappy and anxious to start with their cancer treatment. Although, the fertility preservation prepared some for the upcoming cancer treatment, they were disappointed about their total oocytes harvested. Women reported that undergoing fertility preservation provided some sense of emotional avoidance, this was only temporary, and they had to face their cancer and cancer treatment.

At the time of the interviews, two women had used their preserved material successfully, while eight were still waiting for the right time to access their frozen oocytes. Furthermore, two of the other women reported having a child before they received their cancer diagnosis; however, these women expressed similar thoughts and concerns to those who did not have any children at the time of the interview.

7.2 Limitations

During the study, the first limitation which I encountered involved obtaining sufficient research for the literature review. During the initial search for research that focused on the subjective experience of fertility preservation, very little research could be sourced. I located several international research studies on the subjective experience of fertility preservation; however, I was not able to obtain any research pertinent to this topic within the South African context. While research exists on the medical aspects of fertility preservation and the techniques thereof, there is no published research on the psychological aspects of fertility preservation in South Africa. Nearly all the research reviewed were from international studies using samples which may have been different compared to women within South Africa receiving treatment in South African health care systems.

A second limitation that I encountered in this study involved the recruitment of sufficient participants. Initially, I approached four fertility clinics to seek assistance in participant recruitment; however, at the end only two clinics managed to recruit participants. Another factor which contributed to the challenges experienced during recruitment could have been that several participants were not residing within Johannesburg or the Western Cape, even though they received treatment at these clinics. Due to the sensitivity of this topic, many women could have been reluctant to talk about their experience, which could have contributed to the lack of participants willing to participate in this study. Since the fertility clinic was the first point of contact for the participants, it may have been that recruitment emails were missed by the potential participant.

Currently, fertility preservation within South Africa is not funded through any organisation or government, making this a process for the privilege. As this process is for those who have enough personal resources to undertake fertility preservation, the sample demographics may not be a representation of all women in South Africa. Nearly all the participants revealed positive attitudes and interactions from the private fertility clinic from which they were recruited, which if it had not been a private facility, they may have had different experiences.

7.3 Recommendations

Based on the findings of my study, I would like to make a few recommendations for future research and for clinical practice.

7.3.1. Recommendations for the research setting

Internationally and within South Africa much research has focused the lived experience of cancer, yet a dearth of research exists on the lived experience of fertility preservation particularly among cancer patients. In addition, a variety of international research has focused on the medical aspects of fertility preservation, but very little to no research has been conducted on the psychological aspects thereof. Thus, it is recommended that more research is needed that focuses on the psychological impact of fertility preservation on cancer patients. Since this study only primarily focused on the account of female participants, more research should be conducted with a wider sample, such as oncologists, fertility specialists and male cancer patients on the barriers and facilitators associated with fertility preservation.

7.3.2. Recommendations for the clinical setting

It was evident that undergoing fertility preservation prior to cancer treatment improved the overall quality of life of individuals, therefore more research is needed on the overall impact that fertility preservation has on cancer patients' general quality of life and well-being. Currently fertility preservation is a process for the privileged because of the costs associated with it. Therefore, more research is needed to create an awareness among the healthcare system within South Africa to make fertility preservation more accessible for lower income households.

Importantly, the participants form this study reported that they were unaware of the impact that cancer treatment had on their fertility. Therefore, I would recommend that more research is needed to create awareness on the impact of cancer treatments. It was apparent in this study that the women had very little to no knowledge on fertility preservation. I would recommend that more research is conducted on the physical, emotional, and social side-effects of undergoing fertility preservation and what the process entails. This will provide fertility specialists with adequate information that they can share with potential clients. Specialists should provide more detailed information about the potential risks involved in an appropriate manner which individuals are able to understand to minimize anxiety, confusion and fear about the process and the risks involved. Moreover, I would recommend that fertility specialists refer patients for psychological support where needed.

7.4 Conclusion

This study explored the subjective experience of fertility preservation among female cancer survivors within private clinic facilitates in the Western Cape and Johannesburg. The 10 women who participated in this study provided exclusive and valuable accounts of their cancer and fertility preservation processes, which allowed me as the primary researcher to infer several conclusions regarding their experiences. Receiving a cancer diagnosis during reproductive years brought upon shock, distress, and anger for the women in this study, whilst at the same time being informed about possible infertility due to cancer treatment. While a few women reported a sense of urgency to undergo cancer treatment in the fear of their cancer metastasizing, all the women in this study delayed cancer treatment to accommodate for fertility preservation. Women reported that the importance of biological motherhood was their main reason for undertaking fertility preservation. However, women reported that the fertility preservation was a combination of positive and negative experiences, all the women entered the process anxious and hopeful, while only some ended the process feeling happy and relieved. It was apparent that even though all the women underwent similar hormone treatment and oocyte harvesting regimes, they all had similar but also different experiences and there was no single unified experience. However, the process was perceived as positive among all the women and provided them with some sense optimism about their future.

References

A. Zomerlei, T., A. Block, E., L. Caughran, J., & L. Keto, J. (2018). Perceived sexual dysfunction in breast cancer survivors. *Frontiers in Women's Health*, *3*(3), 1–4. https://doi.org/10.15761/fwh.1000146

Abegaz, T. M., Ayele, A. A., & Gebresillassie, B. M. (2018). Health Related Quality of Life of Cancer Patients in Ethiopia. *Journal of Oncology*, *2018*. https://doi.org/10.1155/2018/1467595

Abraham, C., & Sheeran, P. (2014a). The health belief model. *Cambridge Handbook of Psychology, Health and Medicine, Second Edition*, *June*, 97–102. https://doi.org/10.1017/CBO9780511543579.022

Abraham, C., & Sheeran, P. (2014b). The health belief model. *Cambridge Handbook of Psychology, Health and Medicine, Second Edition*, *January*, 97–102. https://doi.org/10.1017/CBO9780511543579.022

Abraham, C., & Sheeran, P. (2014c). The health belief model. *Cambridge Handbook of Psychology, Health and Medicine, Second Edition*, *June*, 97–102. https://doi.org/10.1017/CBO9780511543579.022

Adams, W. C. (2015). Conducting Semi-Structured Interviews. *Handbook of Practical Program Evaluation: Fourth Edition*, *August*, 492–505. https://doi.org/10.1002/9781119171386.ch19

Alamin, S., Allahyari, T., Ghorbani, B., Sadeghitabar, A., & Karami, M. T. (2020). Failure in identity building as the main challenge of infertility: A qualitative study. *Journal of Reproduction and Infertility*, *21*(1), 49–58.

Alase, A. (2017). The Interpretative Phenomenological Analysis (IPA): A Guide to a Good Qualitative Research Approach. *International Journal of Education and Literacy Studies*, *5*(2), 9. https://doi.org/10.7575/aiac.ijels.v.5n.2p.9

Almigbal, T. H., Almutairi, K. M., Fu, J. B., Vinluan, J. M., Alhelih, E., Alonazi, W. B., Batais, M. A., Alodhayani, A. A., & Mubaraki, M. A. (2019). Assessment of psychological distress among cancer patients undergoing radiotherapy in Saudi Arabia. *Psychology Research and Behavior Management*, *12*, 691–700. https://doi.org/10.2147/PRBM.S209896

Althof, S. E., Leiblum, S. R., Chevret-Measson, M., Hartmann, U., Levine, S. B., McCabe, M., Plaut, M., Rodrigues, O., & Wylie, K. (2005). Psychological and interpersonal dimensions of sexual function and dysfunction. *Journal of Sexual Medicine*, *2*(6), 793–800. https://doi.org/10.1111/j.1743-6109.2005.00145.x

American Cancer Society. (2018). *Global Cancer Facts & Figures 4th Edition*. https://doi.org/10.1787/health_glance_eur-2018-graph47-en

Angarita, A. M., Johnson, C. A., Fader, A. N., & Christianson, M. S. (2016). Fertility Preservation: A Key Survivorship Issue for Young Women with Cancer. *Frontiers in Oncology*, *6*(April), 1–10. https://doi.org/10.3389/fonc.2016.00102

Armuand, G. M., & Wettergren, L. (2014). *Desire for children , difficulties achieving a pregnancy , and infertility distress 3 to 7 years after cancer diagnosis*. 2805–2812. https://doi.org/10.1007/s00520-014-2279-z

Arora, A., Saini, S., Nautiyal, V., Verma, S., Gupta, M., Kalra, B., & Ahmad, M. (2019). Cancer pain, anxiety, and depression in admitted patients at a tertiary care hospital: A prospective observational study. *Indian Journal of Palliative Care*, *25*(4), 562–566. https://doi.org/10.4103/IJPC.IJPC_4_19

AS, Z. (2010). Psychological Distress Among Infertile Women: Exploring Biopsychosocial Response To Infertility. *Malaysian Journal of Psychiatry*, *19*(2).

Aspers, P., & Corte, U. (2019). What is Qualitative in Qualitative Research. *Qualitative Sociology*, *42*(2), 139–160. https://doi.org/10.1007/s11133-019-9413-7

Assi, J., Santos, J., Bonetti, T., Serafini, P. C., Motta, E. L. A., & Chehin, M. B. (2018). Psychosocial benefits of fertility preservation for young cancer patients. *Journal of Assisted Reproduction and Genetics*, *35*(4), 601–606. https://doi.org/10.1007/s10815-018-1131-7

Attia, M., & Edge, J. (2017). Be(com)ing a reflexive researcher: a developmental approach to research methodology. *Open Review of Educational Research*, *4*(1), 33–45. https://doi.org/10.1080/23265507.2017.1300068

Bard, M., & Sutherland, A. (n.d.). Psychological impact of cancer and its treatments. *Revista de Sanidad Militar*, *8*(1–3), 3–9.

Batool, S. S., & de Visser, R. O. (2016a). Experiences of Infertility in British and Pakistani Women: A Cross-Cultural Qualitative Analysis. *Health Care for Women International*, *37*(2), 180–196. https://doi.org/10.1080/07399332.2014.980890

Batool, S. S., & de Visser, R. O. (2016b). Experiences of Infertility in British and Pakistani Women: A Cross-Cultural Qualitative Analysis. *Health Care for Women International*, *37*(2), 180–196. https://doi.org/10.1080/07399332.2014.980890

Bedaiwy, M. A., & Falcone, T. (2006). Fertility preservation in cancer patients. *Women's Health*, *2*(3), 479–489. https://doi.org/10.2217/17455057.2.3.479

Berger, R. (2015). Now I see it, now I don't: researcher's position and reflexivity in qualitative research. *Qualitative Research*, *15*(2), 219–234. https://doi.org/10.1177/1468794112468475

Bickman, L., & Rog, D. (2014). The SAGE Handbook of Applied Social Research Methods. *The SAGE Handbook of Applied Social Research Methods*, 214–253. https://doi.org/10.4135/9781483348858

Binotto, M., Reinert, T., Werutsky, G., Zaffaroni, F., & Schwartsmann, G. (2020). Health-related quality of life before and during chemotherapy in patients with early-stage breast cancer. *Ecancermedicalscience*, *14*, 1–11. https://doi.org/10.3332/ECANCER.2020.1007

Boivin, J., & Schmidt, L. (2005). Infertility-related stress in men and women predicts treatment outcome 1 year later. *Fertility and Sterility*, *83*(6), 1745–1752. https://doi.org/10.1016/j.fertnstert.2004.12.039

Born, S. L. (2015). *The Fertility Problem Inventory and Infertility- Related Stress : A Case Study*. *21*(3), 497–520.

Boz, İ., Özçetin, E., & Teskereci, G. (2018). İnfertilitede Anne Olma: Kuramsal Bir Analiz. *Psikiyatride Guncel Yaklasimlar - Current Approaches in Psychiatry*, *10*(4), 496–511. https://doi.org/10.18863/pgy.382342

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Brison, D. R. (2002). Fertility preservation in cancer patients. *Human Fertility*, *5*(3), 99–101. https://doi.org/10.1080/1464727022000199002

Center for Disease Control and Prevention. (2017). FACTS ABOUT GYNECOLOGIC CANCER. *Centers for Disease Control and Prevention's (CDC) Inside Knowledge: Get the Facts About Gynecologic Cancer Campaign.*, *22–0098*, 1–22.

Champion, V. L., & Skinner, C. S. (2008). The health belief model. In *Health behavior and health education: Theory, research, and practice, 4th ed.* (pp. 45–65). Jossey-Bass.

Chavan, V. (2013). STAGE IV CANCER: BATTLE NOT LOST YET ! *Www.Pharmatutor.Org/*.

Chiou, Y. J., Chiu, N. M., Wang, L. J., Li, S. H., Lee, C. Y., Wu, M. K., Chen, C. C., Wu, Y. S., & Lee, Y. (2016). Prevalence and related factors of psychological distress among cancer inpatients using routine distress thermometer and chinese health questionnaire screening. *Neuropsychiatric Disease and Treatment*, *12*, 2765–2773. https://doi.org/10.2147/NDT.S118667

Clay, L. K. (2013). The Lived Experiences of African American Women with Breast Cancer: Implications for Counselors. *University of New Orleans Theses and Dissertations*.

Coetzee, B., Roomaney, R., Smith, P., & Daniels, J. (2019). Exploring breast cancer diagnosis and treatment experience amongst a sample of South African women who access primary healthcare. *South African Journal of Psychology*, 846–847. https://doi.org/10.1057/978-1-349-95943-3_873

Connelly, L. M. (2016). Trustworthiness in Qualitative Research. *MedSurg Nursing*, *25*(6), 435–437.

Conner, M., & Norman, P. (2006). Predicting Health Behaviour: reseaarch and practice with social congnition model. *Predicting Health Behaviour*, 172–182.

Cresswell, J. W. (2006). *Five Qualitative Approach to Inquiry*. 53–84.

Creswell, J. (2012). Five Qualitative Approaches to Inquiry XXXXX. *Qualitative Inquiry and Research Design: Choosing among Five Approaches.*, 53–84.

Croson, E., & Keim-Malpass, J. (2016). Grief and Gracefulness Regarding Cancer Experiences Among Young Women. *Oncology Nursing Forum*, *43*(6), 747–753. https://doi.org/10.1188/16.ONF.747-753

Cserepes, R. E., & Bugán, A. (2015a). *Psychological characteristics of Hungarian infertile couples on personal , couple and sociocultural levels By Réka Eszter Cserepes MA Supervisor : Antal Bugán PhD , CSc*. 1–102.

Cserepes, R. E., & Bugán, A. (2015b). *Psychological characteristics of Hungarian infertile couples on personal , couple and sociocultural levels By Réka Eszter Cserepes MA Supervisor : Antal Bugán PhD , CSc*. 1–102.

Cserepes, R. E., & Bugán, A. (2015c). *Psychological characteristics of Hungarian infertile couples on personal , couple and sociocultural levels By Réka Eszter Cserepes MA Supervisor : Antal Bugán PhD , CSc*. 1–102.

Dahhan, T., van der Veen, F., Bos, A. M. E., Goddijn, M., & Dancet, E. A. F. (2021). The experiences of women with breast cancer who undergo fertility preservation. *Human Reproduction Open*, *2021*(2), 1–7. https://doi.org/10.1093/hropen/hoab018

Daly, C., Micic, S., Facey, M., Speller, B., Yee, S., Kennedy, E. D., Corter, A. L., & Baxter, N. N. (2019). A review of factors affecting patient fertility preservation discussions & decision-making from the perspectives of patients and providers. *European Journal of Cancer Care*, *28*(1), 1–11. https://doi.org/10.1111/ecc.12945

David, S., & Orwig, K. E. (2017). Fertility preservation in cancer patients. *The Biology of Mammalian Spermatogonia*, *90*(October 2012), 315–341. https://doi.org/10.1007/978-1-4939-7505-1_13

Dayal, M. (2012). Fertility preservation options for female cancer patients: A systematic review. *J Fert In Vitro*, *02*(04), 67–74. https://doi.org/10.4172/2165-7491.1000110

de Carvalho, B. R., Kliemchen, J., & Woodruff, T. K. (2017a). Ethical, moral and other aspects related to fertility preservation in cancer patients. *Jornal Brasileiro de Reproducao Assistida*, *21*(1), 45–48. https://doi.org/10.5935/1518-0557.20170011

de Carvalho, B. R., Kliemchen, J., & Woodruff, T. K. (2017b). Ethical, moral and other aspects related to fertility preservation in cancer patients. *Jornal Brasileiro de Reproducao Assistida*, *21*(1), 45–48. https://doi.org/10.5935/1518-0557.20170011

De Ver Dye, T., Apondi, R., Lugada, E., Kahn, J. G., Sandiford-Day, M. A., & DasBanerjee, T. (2011). A qualitative assessment of beliefs, attitudes, and behaviors related to diarrhea and water filtration in rural kenya. *American Journal of Public Health*, *101*(8), 1515–1520. https://doi.org/10.2105/AJPH.2011.300127

De Vos, M., Smitz, J., & Woodruff, T. K. (2014). Fertility preservation in women with cancer. *The Lancet*, *384*(9950), 1302–1310. https://doi.org/10.1016/S0140-6736(14)60834-5

Dierickx, S., Rahbari, L., Longman, C., Jaiteh, F., & Coene, G. (2018). “I am always crying on the inside”: A qualitative study on the implications of infertility on women’s lives in urban Gambia. *Reproductive Health*, *15*(1), 1–11. https://doi.org/10.1186/s12978-018-0596-2

Dodgson, J. E. (2019). Reflexivity in Qualitative Research. *Journal of Human Lactation*, *35*(2), 220–222. https://doi.org/10.1177/0890334419830990

Donarelli, Z., Lo Coco, G., Gullo, S., Marino, A., Volpes, A., Salerno, L., & Allegra, A. (2016). Infertility-related stress, anxiety and ovarian stimulation: can couples be reassured about the effects of psychological factors on biological responses to assisted reproductive technology? *Reproductive Biomedicine and Society Online*, *3*, 16–23. https://doi.org/10.1016/j.rbms.2016.10.001

Drapeau, A., Marchand, A., & Beaulieu-Prevost, D. (2012). Epidemiology of Psychological Distress. *Mental Illnesses - Understanding, Prediction and Control*, *May 2014*. https://doi.org/10.5772/30872

Duffy, L., & Aquino-Russell, C. (2007). The lived experience of women with cancer: phenomenological findings expressed through poetry. *Canadian Oncology Nursing Journal = Revue Canadienne de Nursing Oncologique*, *17*(4), 193–205. https://doi.org/10.5737/1181912x174193198

Duthie, E. A., Cooper, A., Davis, J. B., Schoyer, K. D., Sandlow, J., Strawn, E. Y., & Flynn, K. E. (2017). A conceptual framework for patient-centered fertility treatment. *Reproductive Health*, *14*(1), 1–10. https://doi.org/10.1186/s12978-017-0375-5

Dyer, K. E., & Quinn, G. P. (2016). Cancer and Fertility Preservation in Puerto Rico: A Qualitative Study of Healthcare Provider Perceptions. *Support Care Cancer*, *24*(8), 3353–3360. https://doi.org/10.1007/s00520-016-3166-6

Dyer, S. J., Abrahams, N., Mokoena, N. E., Lombard, C. J., & van der Spuy, Z. M. (2005). Psychological distress among women suffering from couple infertility in South Africa: A quantitative assessment. *Human Reproduction*, *20*(7), 1938–1943. https://doi.org/10.1093/humrep/deh845

Dyer, S. J., Abrahams, N., Mokoena, N. E., & van der Spuy, Z. M. (2004). “You are a man because you have children”: Experiences, reproductive health knowledge and treatment-seeking behaviour among men suffering from couple infertility in South Africa. *Human Reproduction*, *19*(4), 960–967. https://doi.org/10.1093/humrep/deh195

Ehrbar, V., Urech, C., Alder, J., Harringer, K., Dällenbach, R. Z., Rochlitz, C., & Tschudin, S. (2016). Decision-making about fertility preservation — qualitative data on young cancer patients ’ attitudes and needs. *Archives of Women’s Mental Health*, 695–699. https://doi.org/10.1007/s00737-016-0604-x

Etikan, I. (2016). Comparison of Convenience Sampling and Purposive Sampling. *American Journal of Theoretical and Applied Statistics*, *5*(1), 1. https://doi.org/10.11648/j.ajtas.20160501.11

Fisher, J. R. W., & Hammarberg, K. (2012). Psychological and social aspects of infertility in men: An overview of the evidence and implications for psychologically informed clinical care and future research. *Asian Journal of Andrology*, *14*(1), 121–129. https://doi.org/10.1038/aja.2011.72

Fulford, B., Bunting, L., Tsibulsky, I., & Boivin, J. (2013). The role of knowledge and perceived susceptibility in intentions to optimize fertility: findings from the International Fertility Decision-Making Study (IFDMS). *Human Reproduction (Oxford, England)*, *28*(12), 3253–3262. https://doi.org/10.1093/humrep/det373

Gameiro, S., Biovin, J., ter Keurst, A., Figueiredo, B., & Sousa-Leite, M. (2019). Women's attitudes and beliefs about using fertility preservation to prevent age-related fertility decline - a two-year follow-up. *Pa Ti En t Educ a Tion a Nd Couns Eling*, *102*(9).

Gardino, S., Rodriguez, S., & Campo-Engelstein, L. (2011). Infertility, cancer, and changing gender norms. *Journal of Cancer Survivorship*, *5*(2), 152–157. https://doi.org/10.1007/s11764-010-0166-2

Gentzler, K. C. (2011). *Motherhood Situation and Life Satisfaction: Are Reasons for Having No Children Important?*

Gorman, J. R., Drizin, J. H., Mersereau, J. E., Su, I., Sciences, B. H., Diego, S., & Cancer, M. (2020). *Applying behavioral theory to understand fertility consultation uptake after cancer*. *28*(4), 822–829. https://doi.org/10.1002/pon.5027.Applying

Gracia, C., & Woodruff, T. K. (2012). Oncofertility medical practice: Clinical issues and implementation. *Oncofertility Medical Practice: Clinical Issues and Implementation*, 1–290. https://doi.org/10.1007/978-1-4419-9425-7

Guan Ng, C., Mohamed, S., Kaur, K., Sulaiman, A. H., Zainal, N. Z., & Taib, N. A. (2017). Perceived distress and its association with depression and anxiety in breast cancer patients. *PLoS ONE*, *12*(3), 1–7. https://doi.org/10.1371/journal.pone.0172975

Guenther, J., Stiles, A., & Champion, J. D. (2012). The lived experience of ovarian cancer: A phenomenological approach. *Journal of the American Academy of Nurse Practitioners*, *24*(10), 595–603. https://doi.org/10.1111/j.1745-7599.2012.00732.x

Guidry, J. P. D., Carlyle, K. E., Larose, J. G., Perrin, P., Messner, M., & Ryan, M. (2019). Using the health belief model to analyze instagram posts about Zika for public health communications. *Emerging Infectious Diseases*, *25*(1), 179–180. https://doi.org/10.3201/eid2501.180824

Gunawan, J. (2015). Ensuring Trustworthiness in Qualitative Research. *Belitung Nursing Journal-- Belitung Raya Publisher Gunawan J. Belitung Nursing Journal*, *11*(11), 10–11.

Hall, K. S. (2012). The Health Belief Model Can Guide Modern Contraceptive Behavior Research and Practice. *Journal of Midwifery and Women's Health*, *57*(1), 74–81. https://doi.org/10.1111/j.1542-2011.2011.00110.x

Hammarberg, K. (2001). Women's experience of IVF: a follow-up study. *Human Reproduction*, *16*(2), 374–383. https://doi.org/10.1093/humrep/16.2.374

Harries, J., Scott, S. E., Walter, F. M., Mwaka, A. D., & Moodley, J. (2020). Women's appraisal, interpretation and help-seeking for possible symptoms of breast and cervical cancer in South Africa: a qualitative study. *BMC Women's Health*, *20*(1), 251. https://doi.org/10.1186/s12905-020-01120-4

Hasanpoor, S. B., Simbar, M., & Vedadhir, A. (2014). *The emotional-psychological consequences of infertility among infertile women seeking treatment: Results of a qualitative study*. *12*(2), 131–138.

Hasanpoor-Azghdy, S. B., Simbar, M., & Vedadhir, A. (2014). The emotional-psychological consequences of infertility among infertile women seeking treatment: Results of a qualitative study. *Iranian Journal of Reproductive Medicine*, *12*(2), 131–138.

Hassen, A. M., Taye, G., Gizaw, M., & Hussien, F. M. (2019a). Quality of life and associated factors among patients with breast cancer under chemotherapy at Tikur Anbessa specialized hospital, Addis Ababa, Ethiopia. *PLoS ONE*, *14*(9), 1–13. https://doi.org/10.1371/journal.pone.0222629

Hassen, A. M., Taye, G., Gizaw, M., & Hussien, F. M. (2019b). Quality of life and associated factors among patients with breast cancer under chemotherapy at Tikur Anbessa specialized hospital, Addis Ababa, Ethiopia. *PLoS ONE*, *14*(9), 1–13. https://doi.org/10.1371/journal.pone.0222629

Hawkey, A., Ussher, J. M., Perz, J., & Parton, C. (2021). Talking but not always understanding: couple communication about infertility concerns after cancer. *BMC Public Health*, *21*(1), 1–14. https://doi.org/10.1186/s12889-021-10188-y

Hershberger, P. E., Sipsma, H., Finnegan, L., & Hirshfeld-Cytron, J. (2016). Reasons Why Young Women Accept or Decline Fertility Preservation Following Cancer Diagnosis HHS Public Access. *J Obstet Gynecol Neonatal Nurs*, *45*(1), 123–134. https://doi.org/10.1016/j.jogn.2015.10.003

Hershberger, P. E., Sipsma, H., Finnegan, L., & Hirshfeld-cytron, J. (2017). Reasons Why Young Women Accept or Decline Fertility Preservation Following Cancer Diagnosis. *J Obstet Gynecol Neonatal Nurs*, *45*(1), 123–134. https://doi.org/10.1016/j.jogn.2015.10.003.Reasons

Hoeg, D., Schmidt, L., & Kt, M. (2015). *Cancer and Fertility – A Qualitative Pilot Study of Young Female Cancer Patients ' Experiences with Fertility Counseling and Fertility Preservation*. *2*(1), 1–4.

Hong, J. S., & Tian, J. (2014). Prevalence of anxiety and depression and their risk factors in Chinese cancer patients. *Supportive Care in Cancer, 22*(2), 453–459. https://doi.org/10.1007/s00520-013-1997-y

Inhorn, M. C., Birenbaum-Carmeli, D., & Patrizio, P. (2017). Medical egg freezing and cancer patients' hopes: Fertility preservation at the intersection of life and death. *Social Science and Medicine*, *195*(October), 25–33. https://doi.org/10.1016/j.socscimed.2017.10.031

Inhorn, M. C., & Patrizio, P. (2015). Infertility around the globe: new thinking on gender, reproductive technologies and global movements in the 21st century. *Human Reproduction Update*, *21*(4), 411–426. https://doi.org/10.1093/humupd/dmv016

Izycki, D., Woźniak, K., & Izycka, N. (2016a). Consequences of gynecological cancer in patients and their partners from the sexual and psychological perspective. *Przeglad Menopauzalny*, *15*(2), 112–116. https://doi.org/10.5114/pm.2016.61194

Izycki, D., Woźniak, K., & Izycka, N. (2016b). Consequences of gynecological cancer in patients and their partners from the sexual and psychological perspective. *Przeglad Menopauzalny*, *15*(2), 112–116. https://doi.org/10.5114/pm.2016.61194

Izycki, D., Woźniak, K., & Izycka, N. (2016c). Consequences of gynecological cancer in patients and their partners from the sexual and psychological perspective. *Przeglad Menopauzalny*, *15*(2), 112–116. https://doi.org/10.5114/pm.2016.61194

Janz, N. K., & Becker, M. H. (1984). The Health Belief Model: A Decade Later. *Health Education & Behavior*, *11*(1), 1–47. https://doi.org/10.1177/109019818401100101

Jeunette, L. (2016). *The Ethical Analysis of the Connection between Hope and Fertility Preservation*.

Jones, B. P., Kasaven, L., L'Heveder, A., Jalmbrant, M., Green, J., Makki, M., Odia, R., Norris, G., Bracewell Milnes, T., Saso, S., Serhal, P., & Ben Nagi, J. (2020). Perceptions, outcomes, and regret following social egg freezing in the UK; a cross-sectional survey. *Acta Obstetricia et Gynecologica Scandinavica*, *99*(3), 324–332. https://doi.org/10.1111/aogs.13763

Jones, C. L., Jensen, J. D., Scherr, C. L., Brown, N. R., Christy, K., & Weaver, J. (2016). The Health Belief Model as an Explanatory Framework in Communication Research. *Health Communication*, *30*(6), 566–576. https://doi.org/10.1080/10410236.2013.873363.The

Jones, G., Hughes, J., Mahmoodi, N., Smith, E., Skull, J., & Ledger, W. (2017a). What factors hinder the decision-making process for women with cancer and contemplating fertility preservation treatment? *Human Reproduction Update*, *23*(4), 433–457. https://doi.org/10.1093/humupd/dmx009

Jones, G., Hughes, J., Mahmoodi, N., Smith, E., Skull, J., & Ledger, W. (2017b). What factors hinder the decision-making process for women with cancer and contemplating fertility preservation treatment? *Human Reproduction Update*, *23*(4), 433–457. https://doi.org/10.1093/humupd/dmx009

Jones, G., Hughes, J., Mahmoodi, N., Smith, E., Skull, J., & Ledger, W. (2017c). What factors hinder the decision-making process for women with cancer and contemplating fertility preservation treatment? *Human Reproduction Update*, *23*(4), 433–457. https://doi.org/10.1093/humupd/dmx009

Kagee, A., Roomaney, R., & Knoll, N. (2018). Psychosocial predictors of distress and depression among South African breast cancer patients. *Psycho-Oncology*, *27*(3), 908–914. https://doi.org/10.1002/pon.4589

Kelvin, J. F. (2016). Fertility preservation before cancer treatment: Options, strategies, and resources. *Clinical Journal of Oncology Nursing*, *20*(1), 44–51. https://doi.org/10.1188/16.CJON.44-51

Kimati, C. T., Montagnini, H. L., Bonetti, T. C., Serafini, P. C., Motta, E., & Domingues, T. S. (2016). The psycho-emotional impact of women receiveing donor eggs and the influence on decision treatment. *Fertility and Sterility*, *106*(3), e117. https://doi.org/10.1016/j.fertnstert.2016.07.352

King, A., Kaighobadi, F., Winecoff, A., & Lee, A. (2016). Brief report: A health belief model approach to men’s assessment of a novel long-acting contraceptive. *Cogent Medicine*, *3*(1), 1250320. https://doi.org/10.1080/2331205x.2016.1250320

Komatsu, H., Yagasaki, K., & Yamauchi, H. (2018a). Fertility decision-making under certainty and uncertainty in cancer patients. *Sexual and Reproductive Healthcare*, *15*(December 2017), 40–45. https://doi.org/10.1016/j.srhc.2017.12.002

Komatsu, H., Yagasaki, K., & Yamauchi, H. (2018b). Fertility decision-making under certainty and uncertainty in cancer patients. *Sexual and Reproductive Healthcare*, *15*(July 2017), 40–45. https://doi.org/10.1016/j.srhc.2017.12.002

Komatsu, H., Yagasaki, K., & Yamauchi, H. (2018c). Fertility decision-making under certainty and uncertainty in cancer patients. *Sexual and Reproductive Healthcare*, *15*(December 2017), 40–45. https://doi.org/10.1016/j.srhc.2017.12.002

Lakatos, E., Szigeti, J. F., Ujma, P. P., Sexty, R., & Balog, P. (2017). Anxiety and depression among infertile women: A cross-sectional survey from Hungary. *BMC Women's Health*, *17*(1), 1–9. https://doi.org/10.1186/s12905-017-0410-2

Lambert, M., Mendenhall, E., Kim, A. W., Cubasch, H., Joffe, M., & Norris, S. A. (2020). Health system experiences of breast cancer survivors in urban South Africa. *Women's Health*, *16*. https://doi.org/10.1177/1745506520949419

Larsen, U., & Hollos, M. (2012). *The Importance of Motherhood: A study of infertility in urban Northern Tanzania*. *7*, 3–30.

Letherby, G. (1999a). Other than mother and mothers as others. *Women's Studies International Forum*, *22*(3), 359–372. https://doi.org/10.1016/s0277-5395(99)00028-x

Letherby, G. (1999b). Other than mother and mothers as others. *Women's Studies International Forum*, *22*(3), 359–372. https://doi.org/10.1016/s0277-5395(99)00028-x

Letherby, G. (1999c). Other than mother and mothers as others. *Women's Studies International Forum*, *22*(3), 359–372. https://doi.org/10.1016/S0277-5395(99)00028-X

Levine, J., Canada, A., & Stern, C. J. (2010). Fertility preservation in adolescents and young adults with cancer. *Journal of Clinical Oncology*, *28*(32), 4831–4841. https://doi.org/10.1200/JCO.2009.22.8312

Liu, J., Xu Peh, C., Chua, S. M., & Mahendran, R. (2017). Emotional Distress in Newly Diagnosed Cancer Outpatients: Do Depression and Anxiety Predict Mortality and Psychosocial Outcomes After 1 Year? *Journal of Depression and Anxiety*, *06*(03). https://doi.org/10.4172/2167-1044.s11-005

Logan, S., & Anazodo, A. (2019). The psychological importance of fertility preservation counseling and support for cancer patients. *Acta Obstetricia et Gynecologica Scandinavica*, *98*(5), 583–597. https://doi.org/10.1111/aogs.13562

Ludwig, A. K., Glawatz, M., Griesinger, G., Diedrich, K., & Ludwig, M. (2006). Perioperative and post-operative complications of transvaginal ultrasound-guided oocyte retrieval: Prospective study of >1000 oocyte retrievals. *Human Reproduction*, *21*(12), 3235–3240. https://doi.org/10.1093/humrep/del278

Mabasa, L. F. (2005). Journal of Psychology in Africa. *Journal of Psychology in Africa*, *15*(2), 143–153.

Maher, J. (2014). *To Be or Not To Be a Mother? Women Negotiating Cultural Representations of Mothering*. *February*. https://doi.org/10.1177/1440783307073931

Maher, J. M., & Saugeres, L. (2007). To be or not to be a mother?: Women negotiating cultural representations of mothering. *Journal of Sociology*, *43*(1), 5–21. https://doi.org/10.1177/1440783307073931

Mai, C. (2008). *Gender Differences in Infertility-Related Stress and the Relationship between Stress and Social Support in Thai Infertile Couples*. *91*(12), 1769–1773.

Makoba, L. T. (2005a). *the Experiences of Infertile Married African Women in South Africa: a Feminist Narrative Inquiry*. *November*, 8–142.

Makoba, L. T. (2005b). *THE EXPERIENCES OF INFERTILE MARRIED AFRICAN WOMEN IN SOUTH AFRICA: A FEMINIST NARRATIVE INQUIRY*. *November*, 8–142.

Malacrida, C., & Boulton, T. N. (2012). *Women's Perceptions of Childbirth "Choices" Article*. *February 2015*. https://doi.org/10.2307/41705724

Malina, A., Błaszkiewicz, A., & Owczarz, U. (2016). Psychosocial aspects of infertility and its treatment. *Ginekologia Polska*, *87*(7), 527–531. https://doi.org/10.5603/GP.2016.0038

Manchester, R. A. (2011). Qualitative research in performing arts medicine. *Medical Problems of Performing Artists*, *26*(2), 63–64. https://doi.org/10.21091/mppa.2011.2010

Marks, D. (2018). *Health Psychology: Theory, Research and Practice. Fifth edition January 2018 Edition: SAGE Publications Projects: Health Psychology. Theory, Research and Practice Health Psychology*.

Martin, L. J. (2010a). Anticipating infertility: Egg freezing, genetic preservation, and risk. *Gender and Society*, *24*(4), 526–545. https://doi.org/10.1177/0891243210377172

Martin, L. J. (2010b). Anticipating infertility: Egg freezing, genetic preservation, and risk. *Gender and Society*, *24*(4), 526–545. https://doi.org/10.1177/0891243210377172

Matsota, P., Kaminioti, E., & Kostopanagiotou, G. (2015). Anesthesia Related Toxic Effects on in Vitro Fertilization Outcome: Burden of Proof. *BioMed Research International, 2015*, 3–5. https://doi.org/10.1155/2015/475362

Matthews, M. L., Hurst, B. S., Marshburn, P. B., Usadi, R. S., Papadakis, M. A., & Sarantou, T. (2012). Cancer, Fertility Preservation, and Future Pregnancy: A Comprehensive

Review. *Obstetrics and Gynecology International*, *2012*, 1–11. https://doi.org/10.1155/2012/953937

McLaren, J. F., & Bates, G. W. (2012a). Fertility preservation in women of reproductive age with cancer. *American Journal of Obstetrics and Gynecology*, *207*(6), 455–462. https://doi.org/10.1016/j.ajog.2012.08.013

McLaren, J. F., & Bates, G. W. (2012b). Fertility preservation in women of reproductive age with cancer. *American Journal of Obstetrics and Gynecology*, *207*(6), 455–462. https://doi.org/10.1016/j.ajog.2012.08.013

McQuillan, J., Greil, A. L., White, L., & Jacob, M. C. (2003). Frustrated Fertility: Infertility and Psychological Distress among Women. *Journal of Marriage and Family*, *65*(4), 1007–1018. https://doi.org/10.1111/j.1741-3737.2003.01007.x

Meacham, E., Orem, J., Nakigudde, G., Zujewski, J. A., & Rao, D. (2016). Exploring stigma as a barrier to cancer service engagement with breast cancer survivors in Kampala, Uganda. *Psycho-Oncology*, *May*, 1206–1211. https://doi.org/10.1002/pon.4215

Mehnert, A., Hartung, T. J., Friedrich, M., Vehling, S., Brähler, E., Härter, M., Keller, M., Schulz, H., Wegscheider, K., Weis, J., Koch, U., & Faller, H. (2018). One in two cancer patients is significantly distressed: Prevalence and indicators of distress. *Psycho-Oncology*, *27*(1), 75–82. https://doi.org/10.1002/pon.4464

Melo, C., Fonseca, A., Moura-Ramos, M., Almeida-Santos, T., & Canavarro, M. C. (2018). Female cancer patients’ perceptions of the fertility preservation decision-making process: An exploratory prospective study. *Journal of Psychosocial Oncology*, *36*(3), 364–381. https://doi.org/10.1080/07347332.2018.1436629

Merwe, E. Van Der. (2010). *Infertility-Related Stress and Specific Aspects*. *March*.

Miller, J. (2005). *SURVIVORS OF CANCER : A PHENOMENOLOGICAL STUDY*. 74.

Mncwabe, N., Hlongwana, K. W., & Ginindza, T. G. (2021). An ethnographic study exploring the experiences of patents living with cancer illness in support group settings in KwaZulu-Natal, South Africa. *African Journal of Primary Health Care and Family Medicine*, *13*(1), 1–8. https://doi.org/10.4102/phcfm.v13i1.2303

Monga, M., Alexandrescu, B., Katz, S. E., Stein, M., & Ganiats, T. (2004). Impact of infertility on quality of life, marital adjustment, and sexual function. *Urology*, *63*(1), 126–130. https://doi.org/10.1016/j.urology.2003.09.015

Monjelat, N., Carretero, M., Implicada, P., Fairstein, G. A., Monjelat, N., & Monjelat, A. (2018). *Infertility-related Distress Following Cancer for Women and Men: A Mixed Method Study*. *15*(2), 1–33. https://doi.org/10.22201/fq.18708404e.2004.3.66178

Moustakas, C. (2011). Research Design and Methodology. *Heuristic Research : Design, Methodology, and Applications*, 38–58. https://doi.org/10.4135/9781412995641.d21

Mulder, L., Loeffen, E. A. H., & Byrne, J. (2016). *Fertility Preservation in Children , Adolescents , and Young Adults With Cancer : Quality of Clinical Practice Guidelines and Variations in Recommendations*. https://doi.org/10.1002/cncr.30047

Mumtaz, Z., Shahid, U., & Levay, A. (2013). Understanding the impact of gendered roles on the experiences of infertility amongst men and women in Punjab. *Reproductive Health*, *10*(1), 1. https://doi.org/10.1186/1742-4755-10-3

Naab, F., & Kwashie, A. A. (2018). *' I don ' t experience any insults , but my wife does ': The concerns of men with infertility in Ghana*. *24*(2), 45–48. https://doi.org/10.7196/SAJOG.2018.v24i2.1278

Nadasen, K. K. (2017). "Everything Happened So Quickly" Living Through Events Immediately Before and After Initial Breast Cancer Diagnosis: An Exploratory Study of the Experiences of a Group of Women in Cape Town, South Africa. *Journal of Womens Health Care*, *06*(04). https://doi.org/10.4172/2167-0420.1000381

Nagórska, M., Bartosiewicz, A., Obrzut, B., & Darmochwał-Kolarz, D. (2019). Gender differences in the experience of infertility concerning polish couples: Preliminary research. *International Journal of Environmental Research and Public Health*, *16*(13). https://doi.org/10.3390/ijerph16132337

Nayak, M. G., George, A., Vidyasagar, M. S., Mathew, S., Nayak, S., Nayak, B. S., Shashidhara, Y. N., & Kamath, A. (2017). Quality of life among cancer patients. *Indian Journal of Palliative Care*, *23*(4), 445–450. https://doi.org/10.4103/IJPC.IJPC_82_17

Neron, M., Bastide, S., Tayrac, R. de, Masia, F., Ferrer, C., Labaki, M., Boileau, L., Letouzey, V., & Huberlant, S. (2019). Impact of gynecologic cancer on pelvic floor disorder symptoms and quality of life: an observational study. *Scientific Reports*, *9*(1), 1–9. https://doi.org/10.1038/s41598-019-38759-5

Ng, C. G., Mohamed, S., Kaur, K., Sulaiman, A. H., Zainal, N. Z., & Taib, N. A. (2017a). Perceived distress and its association with depression and anxiety in breast cancer patients. *PLoS ONE*, *12*(3), 1–10. https://doi.org/10.1371/journal.pone.0172975

Ng, C. G., Mohamed, S., Kaur, K., Sulaiman, A. H., Zainal, N. Z., & Taib, N. A. (2017b). Perceived distress and its association with depression and anxiety in breast cancer patients. *PLoS ONE*, *12*(3), 1–7. https://doi.org/10.1371/journal.pone.0172975

Niedzwiedz, C. L., Knifton, L., Robb, K. A., Katikireddi, S. V., & Smith, D. J. (2019). Depression and anxiety among people living with and beyond cancer: A growing clinical and research priority. *BMC Cancer*, *19*(1), 1–8. https://doi.org/10.1186/s12885-019-6181-4

Nieuwenhuis, F. J. (2015). Martini qualitative research: shaken, not stirred. *BCES Conference Proceedings*, *13*(1), 417–423.

Noyes, N., Knopman, J. M., Long, K., Coletta, J. M., & Abu-rustum, N. R. (2011). Gynecologic Oncology Fertility considerations in the management of gynecologic malignancies. *Gynecologic Oncology*, *120*(3), 326–333. https://doi.org/10.1016/j.ygyno.2010.09.012

Obeidat, H. M., Hamlan, A. M., & Callister, L. C. (2014). Missing Motherhood: Jordanian Women’s Experiences with Infertility. *Advances in Psychiatry*, *2014*, 1–7. https://doi.org/10.1155/2014/241075

Oborn, M. (2014). *The lived experience of being diagnosed and treated for lung cancer in the outpatient departments of an acute care hospital : a psychosocial phenomenological study* . 67.

Ogino, T., & Tanaka, H. (2014). Experimental study on heat and water-vapor transfer in a moisture adsorbing/desorbing, heat-generating fiber material by thermal visualization using an infrared thermography and these numerical analysis. *Journal of Fiber Science and Technology*, *70*(7), 160–166. https://doi.org/10.2115/fiber.70.160

Palaganas, E. C., Sanchez, M. C., Molintas, M. V. P., & Caricativo, R. D. (2017). Reflexivity in qualitative research: A journey of learning. *Qualitative Report*, *22*(2), 426–438.

Panagiotopoulou, N., Ghuman, N., Sandher, R., Herbert, M., & Stewart, J. A. (2018). Barriers and facilitators towards fertility preservation care for cancer patients: a meta-synthesis. *European Journal of Cancer Care*, *27*(1), 1–15. https://doi.org/10.1111/ecc.12428

Pandey, M., Sarita, G. P., Devi, N., Thomas, B. C., Hussain, B. M., & Krishnan, R. (2006a). Distress, anxiety, and depression in cancer patients undergoing chemotherapy. *World Journal of Surgical Oncology*, *4*, 2–6. https://doi.org/10.1186/1477-7819-4-68

Pandey, M., Sarita, G. P., Devi, N., Thomas, B. C., Hussain, B. M., & Krishnan, R. (2006b). Distress, anxiety, and depression in cancer patients undergoing chemotherapy. *World Journal of Surgical Oncology*, *4*, 2–6. https://doi.org/10.1186/1477-7819-4-68

Parton, C., Ussher, J. M., & Perz, J. (2019a). Hope, burden or risk: a discourse analytic study of the construction and experience of fertility preservation in the context of cancer. *Psychology and Health*, *34*(4), 456–477. https://doi.org/10.1080/08870446.2018.1543764

Parton, C., Ussher, J. M., & Perz, J. (2019b). Hope, burden or risk: a discourse analytic study of the construction and experience of fertility preservation in the context of cancer. *Psychology and Health*, *34*(4), 456–477. https://doi.org/10.1080/08870446.2018.1543764

Parton, C., Ussher, J. M., & Perz, J. (2019c). Hope, burden or risk: a discourse analytic study of the construction and experience of fertility preservation in the context of cancer. *Psychology and Health*, *34*(4), 456–477. https://doi.org/10.1080/08870446.2018.1543764

Pascoe, L., & Edvardsson, D. (2013). Benefit finding in cancer: A review of influencing factors and health outcomes. *European Journal of Oncology Nursing*, *17*(6), 760–766. https://doi.org/10.1016/j.ejon.2013.03.005

Paton, A. H. C. (2015). *Issues of autonomy and agency in oncofertility : a socio-bioethical exploration of British adult female cancer patients making oncofertility decisions*. *February*.

Pedro, A. (2015). Coping with Infertility: An Explorative Study of South African Women's Experiences. *Open Journal of Obstetrics and Gynecology*, *05*(01), 49–59. https://doi.org/10.4236/ojog.2015.51008

Pedro, A., & Andipatin, M. (2014). A Qualitative Exploration of South African Women's Psychological and Emotional Experiences of Infertility. *Open Journal of Preventive Medicine*, *04*(05), 327–337. https://doi.org/10.4236/ojpm.2014.45040

Pedro, A., & Faroa, B. D. (2017). Exploring the lived experiences of infertility treatment and care by involuntarily childless women. *Journal of Psychology in Africa*, *27*(3), 267–272. https://doi.org/10.1080/14330237.2017.1321855

Pedro, A., & Mwaba, K. (2013). An exploratory study of South African women's experiences of In Vitro Fertilisation and Embryo Transfer (IVE-ET) at fertility clinics. *Open Journal of Preventive Medicine*, *03*(08), 470–478. https://doi.org/10.4236/ojpm.2013.38063

Pedro, J., Sobral, M. P., Mesquita-Guimarães, J., Leal, C., Costa, M. E., & Martins, M. V. (2017). Couples' discontinuation of fertility treatments: a longitudinal study on demographic, biomedical, and psychosocial risk factors. *Journal of Assisted Reproduction and Genetics*, *34*(2), 217–224. https://doi.org/10.1007/s10815-016-0844-8

Perz, J., Ussher, J., & Gilbert, E. (2014a). Loss, uncertainty, or acceptance: Subjective experience of changes to fertility after breast cancer. *European Journal of Cancer Care*, *23*(4), 514–522. https://doi.org/10.1111/ecc.12165

Perz, J., Ussher, J., & Gilbert, E. (2014b). Loss, uncertainty, or acceptance: Subjective experience of changes to fertility after breast cancer. *European Journal of Cancer Care*, *23*(4), 514–522. https://doi.org/10.1111/ecc.12165

Perz, J., & Ussher, J. M. (2018). Infertility-related Distress Following Cancer for Women and Men: A Mixed Method Study. *Fertility Research and Practice*, 1–33.

Peterson, H. (2015). Fifty shades of freedom. Voluntary childlessness as women's ultimate liberation. *Women's Studies International Forum*, *53*, 182–191. https://doi.org/https://doi.org/10.1016/j.wsif.2014.10.017

Pinelli, S., & Basile, S. (2018). Fertility Preservation: Current and Future Perspectives for Oncologic Patients at Risk for Iatrogenic Premature Ovarian Insufficiency. *BioMed Research International*, *2018*. https://doi.org/10.1155/2018/6465903

Pook, M. (2007). *The Emotional Distress of Infertility*. *14*(6), 1–19.

Quinn, G. P., & Vadaparampil, S. T. (2013). More research, more responsibility: The expansion of duty to warn in cancer patients considering fertility preservation. *American*

Journal of Obstetrics and Gynecology, *209*(2), 98–102. https://doi.org/10.1016/j.ajog.2013.02.031

Quinn, G. P., Vadaparampil, S. T., Jacobsen, P. B., Knapp, C., Keefe, D. L., Bell, G. E., & Fertility, M. (2010). C LINICAL R OUNDS Frozen Hope : Fertility Preservation for Women With Cancer. *Journal of Midwifery & Women's Health*, *55*(2), 175–180. https://doi.org/10.1016/j.jmwh.2009.07.009

Raijmakers, N. J. H., Zijlstra, M., van Roij, J., Husson, O., Oerlemans, S., & van de Poll-Franse, L. V. (2018). Health-related quality of life among cancer patients in their last year of life: results from the PROFILES registry. *Supportive Care in Cancer*, *26*(10), 3397–3404. https://doi.org/10.1007/s00520-018-4181-6

Renu, G., Anice, G., Mamatha, S. P., Baby, S. N., Suneel, C. M., Dinesh, M. N., & Shashidhara, Y. N. (2015). Health Belief Model: A Theoretical Framework For The Development Of Home Safety Supervisory Program In Childhood Injury. *International Journal Of Current Research*, *7*(11), 22691–22695.

Richardson, J. T. E. (1999). The Concepts and Methods of Phenomenographic Research. *Review of Educational Research*, *69*(1), 53–82. https://doi.org/10.3102/00346543069001053

Rodriguez-Wallberg, K. A., & Oktay, K. (2014). Fertility preservation during cancer treatment: Clinical guidelines. *Cancer Management and Research*, *6*(1), 105–117. https://doi.org/10.2147/CMAR.S32380

Ronn, R., & Holzer, H. E. G. (2013). Oncofertility in Canada: The impact of cancer on fertility. *Current Oncology*, *20*(4), 338–344. https://doi.org/10.3747/co.20.1358

Rosemann, B., & Brüning, R. (2014). Towards an Effective Health Interventions Design: An Extension of the Health Belief Model. *Online Journal of Public Health Informatics*, *122*(1–2), 40–41.

Rosenstock, I. M. (1974). Historical Origins of the Health Belief Model. *Health Education & Behavior*, *2*(4), 328–335. https://doi.org/10.1177/109019817400200403

Safaee, A., Moghimi-Dehkordi, B., Zeighami, B., Tabatabaee, H. R., & Pourhoseingholi, M. A. (2008). Predictors of quality of life in breast cancer patients under chemotherapy. *Indian Journal of Cancer*, *45*(3), 107–111. https://doi.org/10.4103/0019-509X.44066

Santre, M., Rathod, J., & Maidapwad, S. (2014). Prevalence of Emotional Distress in Cancer Patients. *IOSR Journal of Dental and Medical Sciences*, *13*(6), 09–14. https://doi.org/10.9790/0853-13650914

Savio, A., & Priyalatha, A. (2014). Lived Experience of Cancer Patients and Their Family Members in a View To Develop a Palliative Care Guideline for the Nursing Personnel. *BMJ Supportive & Palliative Care*, *4*(Suppl 1), A84.2-A84. https://doi.org/10.1136/bmjspcare-2014-000654.242

Seale, C. (2004). Social research methods. *A Reader*, 1–44.

Shalev, C., & Werner-Felmayer, G. (2012). Patterns of globalized reproduction: Egg cells regulation in Israel and Austria. *Israel Journal of Health Policy Research*, *1*(1), 1–12. https://doi.org/10.1186/2045-4015-1-15

Shankar, A., Prasad, N., Roy, S., Chakraborty, A., Biswas, A. S., Patil, J., & Rath, G. K. (2017). Sexual dysfunction in females after cancer treatment: An unresolved issue.

Asian Pacific Journal of Cancer Prevention, *18*(5), 1177–1182. https://doi.org/10.22034/APJCP.2017.18.5.1177

Sharifikia, I., Rohani, C., Estebsari, F., Matbouei, M., Salmani, F., & Hossein-Nejad, A. (2019). Health Belief Model-based Intervention on Women's Knowledge and Perceived Beliefs about Warning Signs of Cancer. *Asia-Pacific Journal of Oncology Nursing*, *6*(4), 431–439. https://doi.org/10.4103/apjon.apjon_32_19

Sharma, M. (2003). *Coping: Strategies* (pp. 442–446).

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, *22*(2), 63–75. https://doi.org/10.3233/EFI-2004-22201

Sheth, K. R., Sharma, V., Helfand, B. T., Cashy, J., Smith, K., Hedges, J. C., Köhler, T. S., Woodruff, T. K., & Brannigan, R. E. (2018). Improved Fertility Preservation Care for Male Patients With Cancer After Establishment of Formalized Oncofertility Program. *JURO*, *187*(3), 979–986. https://doi.org/10.1016/j.juro.2011.10.154

Shian Ming, T., Beck, K. R., Huihua, L., Eng Choon Leslie, L., & Lalit Kumar Radha, K. (2014). Depression and anxiety in cancer patients in a Tertiary General Hospital in Singapore. *Asian Journal of Psychiatry*, *8*(1), 33–37. https://doi.org/10.1016/j.ajp.2013.10.002

Sibeoni, J., Picard, C., Orri, M., Labey, M., Bousquet, G., Verneuil, L., & Revah-Levy, A. (2018). Patients' quality of life during active cancer treatment: A qualitative study. *BMC Cancer*, *18*(1), 1–8. https://doi.org/10.1186/s12885-018-4868-6

Smit, A., Coetzee, B. J. sean, Roomaney, R., Bradshaw, M., & Swartz, L. (2019). Women's stories of living with breast cancer: A systematic review and meta-synthesis of qualitative evidence. *Social Science and Medicine*, *222*(December 2018), 231–245. https://doi.org/10.1016/j.socscimed.2019.01.020

Sousa-Leite, M., Figueiredo, B., ter Keurst, A., Boivin, J., & Gameiro, S. (2019). Women's attitudes and beliefs about using fertility preservation to prevent age-related fertility decline—A two-year follow-up. *Patient Education and Counseling*, *102*(9), 1695–1702. https://doi.org/10.1016/j.pec.2019.03.019

Sreshthaputra, O., Sreshthaputra, R. A., & Vutyavanich, T. (2008). Gender differences in infertility-related stress and the relationship between stress and social support in thai infertile couples. *Journal of the Medical Association of Thailand*, *91*(12), 1769–1773.

Suwankhong, D., & Liamputtong, P. (2018). Physical and emotional experiences of chemotherapy: A qualitative study among women with breast cancer in Southern Thailand. *Asian Pacific Journal of Cancer Prevention*, *19*(2), 521–528. https://doi.org/10.22034/APJCP.2018.19.2.521

Tarkang, E. E., & Zotor, F. B. (2015). Application of the Health Belief Model (HBM) in HIV Prevention: A Literature Review. *Science Publishing Group*, *1*(1), 1–8. https://doi.org/10.11648/j.cajph.20150101.11

Taubman-Ben-Ari, O. (2019). Pathways and barriers to parenthood: Existential concerns regarding fertility, pregnancy, and early parenthood. *Pathways and Barriers to Parenthood: Existential Concerns Regarding Fertility, Pregnancy, and Early Parenthood*, *September*, 1–341. https://doi.org/10.1007/978-3-030-24864-2

Taylor, D., Bury, M., Campling, N., Carter, S., Garfield, S., Newbould, J., & Rennie, T. (2006). A Review of the use of the Health Belief Model (HBM), the Theory of

Reasoned Action (TRA), the Theory of Planned Behaviour (TPB) and the Trans-Theoretical Model (TTM) to study and predict health related behaviour change. *Health (San Francisco), June*, 1–215.

Ter Keurst, A., Boivin, J., & Gameiro, S. (2016). Women's intentions to use fertility preservation to prevent age-related fertility decline. *Reproductive BioMedicine Online, 32*(1), 121–131. https://doi.org/10.1016/j.rbmo.2015.10.007

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, *8*(1), 45. https://doi.org/10.1186/1471-2288-8-45

Thompson, M. (2013). *Infertility's Effect on Stress, Anxiety and Depression from an Adlerian Perspective*. *May*, 1–40.

Tinoco, G., Warsch, S., Glück, S., Avancha, K., & Montero, A. J. (2013). Treating breast cancer in the 21st century: Emerging biological therapies. *Journal of Cancer*, *4*(2), 117–132. https://doi.org/10.7150/jca.4925

Tobin, G. A., & Begley, C. M. (2004). Methodological rigour within a qualitative framework. *Journal of Advanced Nursing*, *48*(4), 388–396. https://doi.org/10.1111/j.1365-2648.2004.03207.x

Tschudin, S., & Bitzer, J. (2009). Psychological aspects of fertility preservation in men and women affected by cancer and other life-threatening diseases. *Human Reproduction Update*, *15*(5), 587–597. https://doi.org/10.1093/humupd/dmp015

Tufford, L., & Newman, P. (2012). Bracketing in qualitative research. *Qualitative Social Work*, *11*(1), 80–96. https://doi.org/10.1177/1473325010368316

Turner, K., Reynolds-May, M. F., Zitek, E. M., Tisdale, R. L., Carlisle, A. B., & Westphal, L. M. (2013). Stress and Anxiety Scores in First and Repeat IVF Cycles: A Pilot Study. *PLoS ONE*, *8*(5), 19–21. https://doi.org/10.1371/journal.pone.0063743

Ulrich, M., & Weatherall, A. (2000a). Motherhood and Infertility: Viewing Motherhood through the Lens of Infertility. *Feminism and Psychology*, *10*(3), 323–336. https://doi.org/10.1177/0959353500010003003

Ulrich, M., & Weatherall, A. (2000b). Motherhood and Infertility: Viewing Motherhood through the Lens of Infertility. *Feminism and Psychology*, *10*(3), 323–336. https://doi.org/10.1177/0959353500010003003

Ulrich, M., & Weatherall, A. (2000c). Motherhood and Infertility: Viewing Motherhood through the Lens of Infertility. *Feminism and Psychology*, *10*(3), 323–336. https://doi.org/10.1177/0959353500010003003

Ussher, J. M., & Perz, J. (2019). Infertility-related distress following cancer for women and men: A mixed method study. *Psycho-Oncology*, *28*(3), 607–614. https://doi.org/10.1002/pon.4990

Vandraas, K. F., Reinertsen, K. V., Kiserud, C. E., & Lie, H. C. (2020). Fear of cancer recurrence among young adult cancer survivors—exploring long-term contributing factors in a large, population-based cohort. *Journal of Cancer Survivorship*. https://doi.org/10.1007/s11764-020-00943-2

Vicary, S., Young, A., & Hicks, S. (2017). A reflective journal as learning process and contribution to quality and validity in interpretative phenomenological analysis. *Qualitative Social Work, 16*(4), 550–565. https://doi.org/10.1177/1473325016635244

Vitale, S. G., La Rosa, V. L., Rapisarda, A. M. C., & Laganà, A. S. (2018a). Fertility preservation in women with gynaecologic cancer: The impact on quality of life and psychological well-being. *Human Fertility*, *21*(1), 35–38. https://doi.org/10.1080/14647273.2017.1339365

Vitale, S. G., La Rosa, V. L., Rapisarda, A. M. C., & Laganà, A. S. (2018b). Fertility preservation in women with gynaecologic cancer: The impact on quality of life and psychological well-being. *Human Fertility*, *21*(1), 35–38. https://doi.org/10.1080/14647273.2017.1339365

Warren, N., Melrose, D. M., Brooker, J. E., & Burney, S. (2018). Psychosocial distress in women diagnosed with gynecological cancer. *Journal of Health Psychology*, *23*(7), 893–904. https://doi.org/10.1177/1359105316640061

Washburn, L. (2014). *Understanding the Health Belief Model*.

Williams, F., & Jeanetta, S. C. (2016a). Lived experiences of breast cancer survivors after diagnosis, treatment and beyond: Qualitative study. *Health Expectations*, *19*(3), 631–642. https://doi.org/10.1111/hex.12372

Williams, F., & Jeanetta, S. C. (2016b). Lived experiences of breast cancer survivors after diagnosis, treatment and beyond: Qualitative study. *Health Expectations*, *19*(3), 631–642. https://doi.org/10.1111/hex.12372

Williams, F., & Jeanetta, S. C. (2016c). Lived experiences of breast cancer survivors after diagnosis, treatment and beyond: Qualitative study. *Health Expectations*, *19*(3), 631–642. https://doi.org/10.1111/hex.12372

Williams, F., & Jeanetta, S. C. (2016d). Lived experiences of breast cancer survivors after diagnosis, treatment and beyond: Qualitative study. *Health Expectations*, *19*(3), 631–642. https://doi.org/10.1111/hex.12372

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. https://doi.org/10.1093/humrep/del401

Woodruff, T. K. (2015). Oncofertility: A grand collaboration between reproductive medicine and oncology. *Reproduction*, *150*(3), S1–S10. https://doi.org/10.1530/REP-15-0163

Yousif Aly, H., & Mohamed, A. E. S. (2017). Depression and Anxiety among Females with Breast Cancer in Sohag University: Results of an Interview Study. *Remedy Publications LLC.*, *2*, 1–7. https://doi.org/| http://remedyoa.com/

Zhu, J., Fang, F., Sjölander, A., Fall, K., Adami, H. O., & Valdimarsdóttir, U. (2017). First-onset mental disorders after cancer diagnosis and cancer-specific mortality: A nationwide cohort study. *Annals of Oncology*, *28*(8), 1964–1969. https://doi.org/10.1093/annonc/mdx265

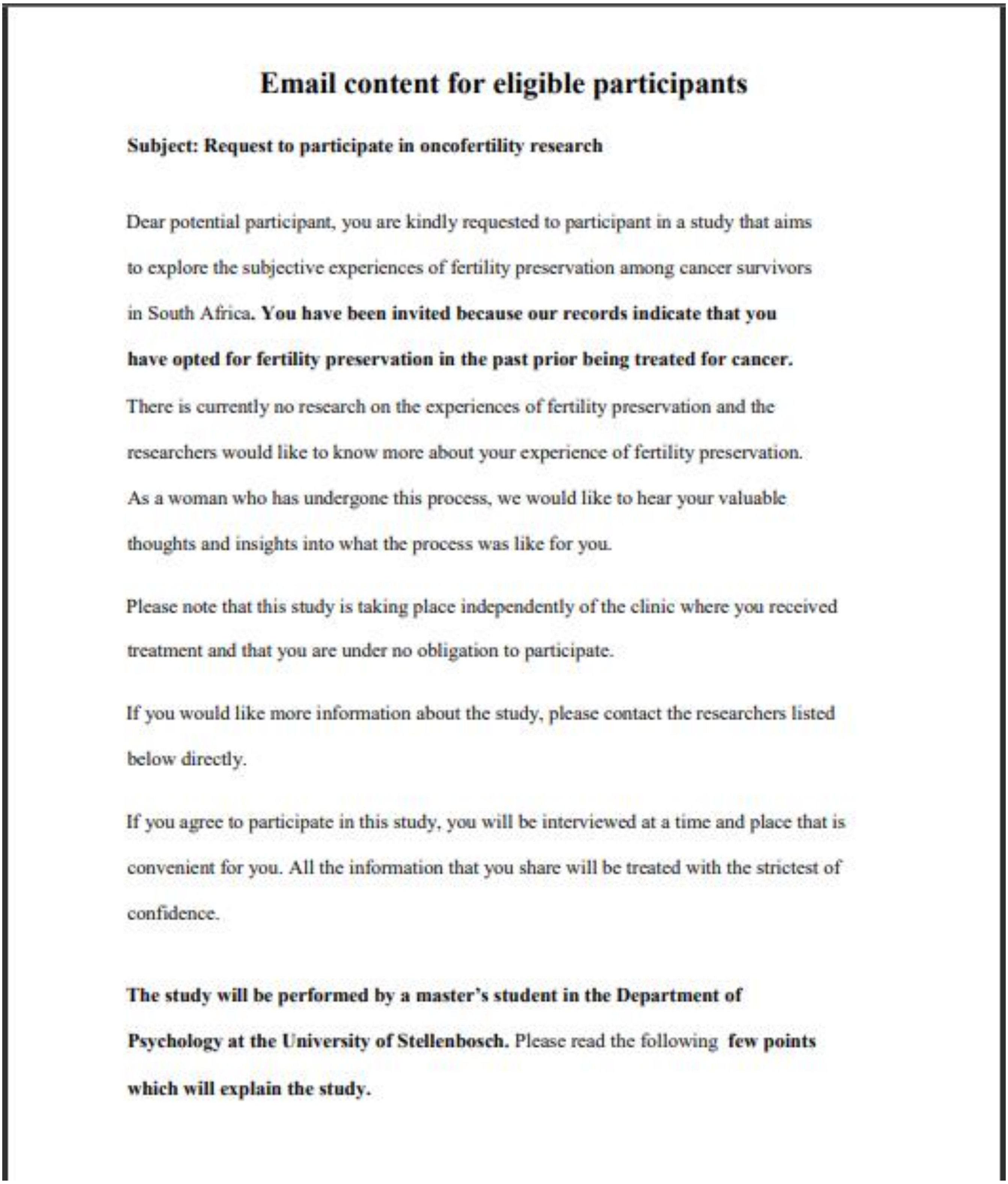
Zuraida, A. (2010). Psychological Distress Among Infertile Women : Exploring Biopsychosocial Response To Infertility. *MJP Online Early*.

Zuraida, A. S. (2010). Psychological distress among infertile women exploring biopsychosocial response to infertility. *Malaysian Journal of Psychiatry*, *19*(2).

Zwane, D. (2021). “Our Beauty Is in Our Breasts”: A Culture-Centered Approach to Understanding Cancer Perceptions in Kwa Zulu Natal, South Africa. *Qualitative Health Research*, *31*(1), 148–159. https://doi.org/10.1177/1049732320960417

Appendices

Appendix A: Recruitment information sheet



Email content for eligible participants

Subject: Request to participate in oncofertility research

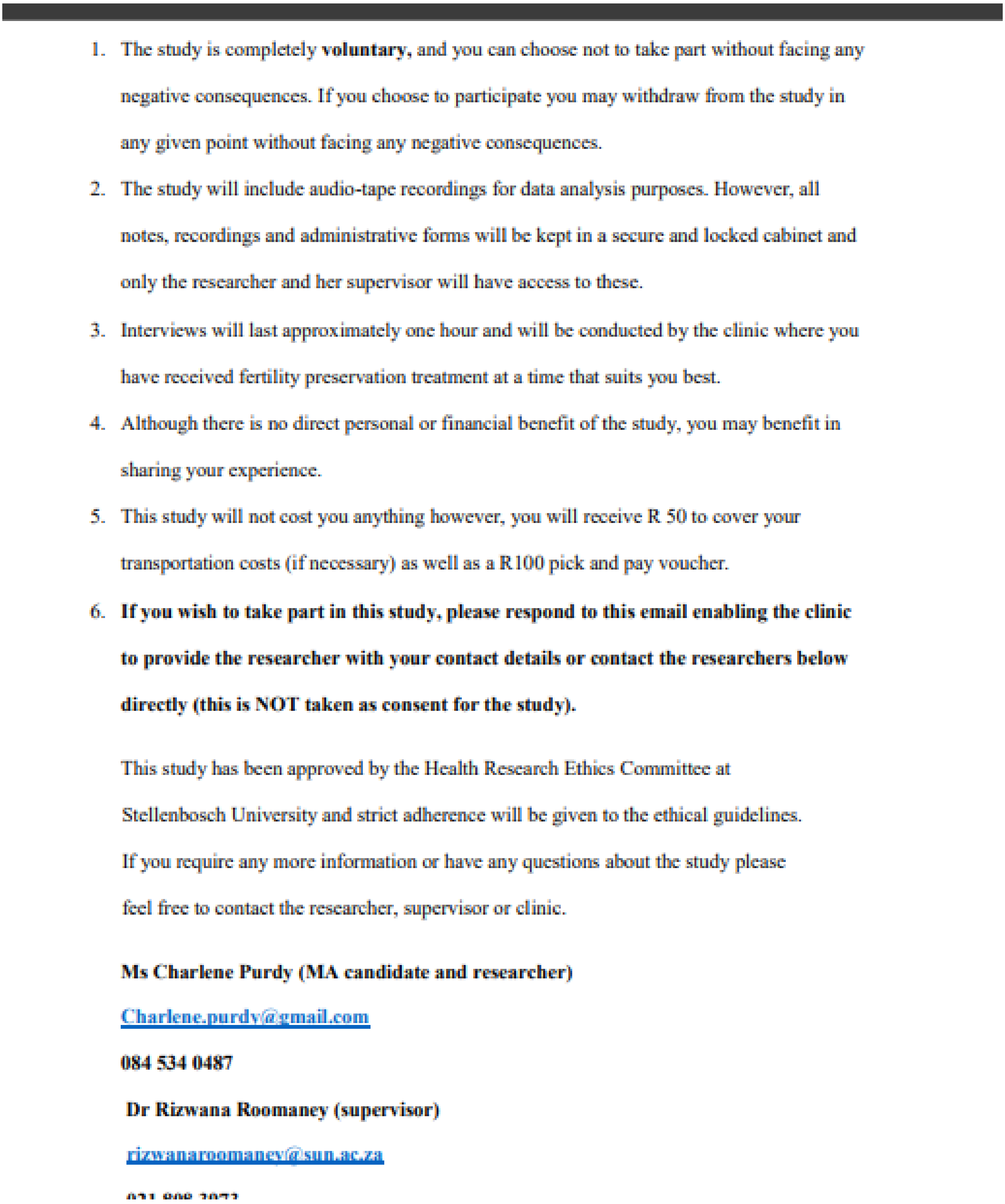
Dear potential participant, you are kindly requested to participant in a study that aims to explore the subjective experiences of fertility preservation among cancer survivors in South Africa. **You have been invited because our records indicate that you have opted for fertility preservation in the past prior being treated for cancer.** There is currently no research on the experiences of fertility preservation and the researchers would like to know more about your experience of fertility preservation. As a woman who has undergone this process, we would like to hear your valuable thoughts and insights into what the process was like for you.

Please note that this study is taking place independently of the clinic where you received treatment and that you are under no obligation to participate.

If you would like more information about the study, please contact the researchers listed below directly.

If you agree to participate in this study, you will be interviewed at a time and place that is convenient for you. All the information that you share will be treated with the strictest of confidence.

The study will be performed by a master's student in the Department of Psychology at the University of Stellenbosch. Please read the following **few points which will explain the study.**



1. The study is completely **voluntary,** and you can choose not to take part without facing any negative consequences. If you choose to participate you may withdraw from the study in any given point without facing any negative consequences.
2. The study will include audio-tape recordings for data analysis purposes. However, all notes, recordings and administrative forms will be kept in a secure and locked cabinet and only the researcher and her supervisor will have access to these.
3. Interviews will last approximately one hour and will be conducted by the clinic where you have received fertility preservation treatment at a time that suits you best.
4. Although there is no direct personal or financial benefit of the study, you may benefit in sharing your experience.
5. This study will not cost you anything however, you will receive R 50 to cover your transportation costs (if necessary) as well as a R100 pick and pay voucher.
6. **If you wish to take part in this study, please respond to this email enabling the clinic to provide the researcher with your contact details or contact the researchers below directly (this is NOT taken as consent for the study).**

This study has been approved by the Health Research Ethics Committee at Stellenbosch University and strict adherence will be given to the ethical guidelines. If you require any more information or have any questions about the study please feel free to contact the researcher, supervisor or clinic.

Ms Charlene Purdy (MA candidate and researcher)

Charlene.purdy@gmail.com

084 534 0487

Dr Rizwana Roomaney (supervisor)

rizwanaroomaney@sun.ac.za

021 808 3073

Appendix B: Ethical clearance for online interviews

UNIVERSITEIT
STELLENBOSCH
UNIVERSITY

Approval Letter
Amendment

08/05/2020

Project ID: 9024

Ethics Reference No: S19/01/022

Project Title: Exploring the Subjective Experiences of Fertility Preservation Among Afrikaans And English-Speaking Cancer Survivors Within Private Clinic Facilities

Dear Miss Charlene Purdy

Your amendment request dated 06/05/2020 12:10 refers.

The Health Research Ethics Committee (HREC) reviewed and approved the amended documentation through an expedited review process.

The following request was reviewed and approved:

- Inclusion of Skype, Zoom, MS teams, and Facetime interviews as a method of data collection.

Where to submit any documentation

Kindly note that the HREC uses an electronic ethics review management system, *Infonetica*, to manage ethics applications and ethics review process. To submit any documentation to HREC, please click on the following link: https://applyethics.sun.ac.za.

Please remember to use your project ID 9024 and ethics reference number S19/01/022 on any documents or correspondence with the HREC concerning your research protocol.

Yours sincerely,

Mrs. Brightness Nxumalo
Coordinator: Health Research Ethics Committee 2

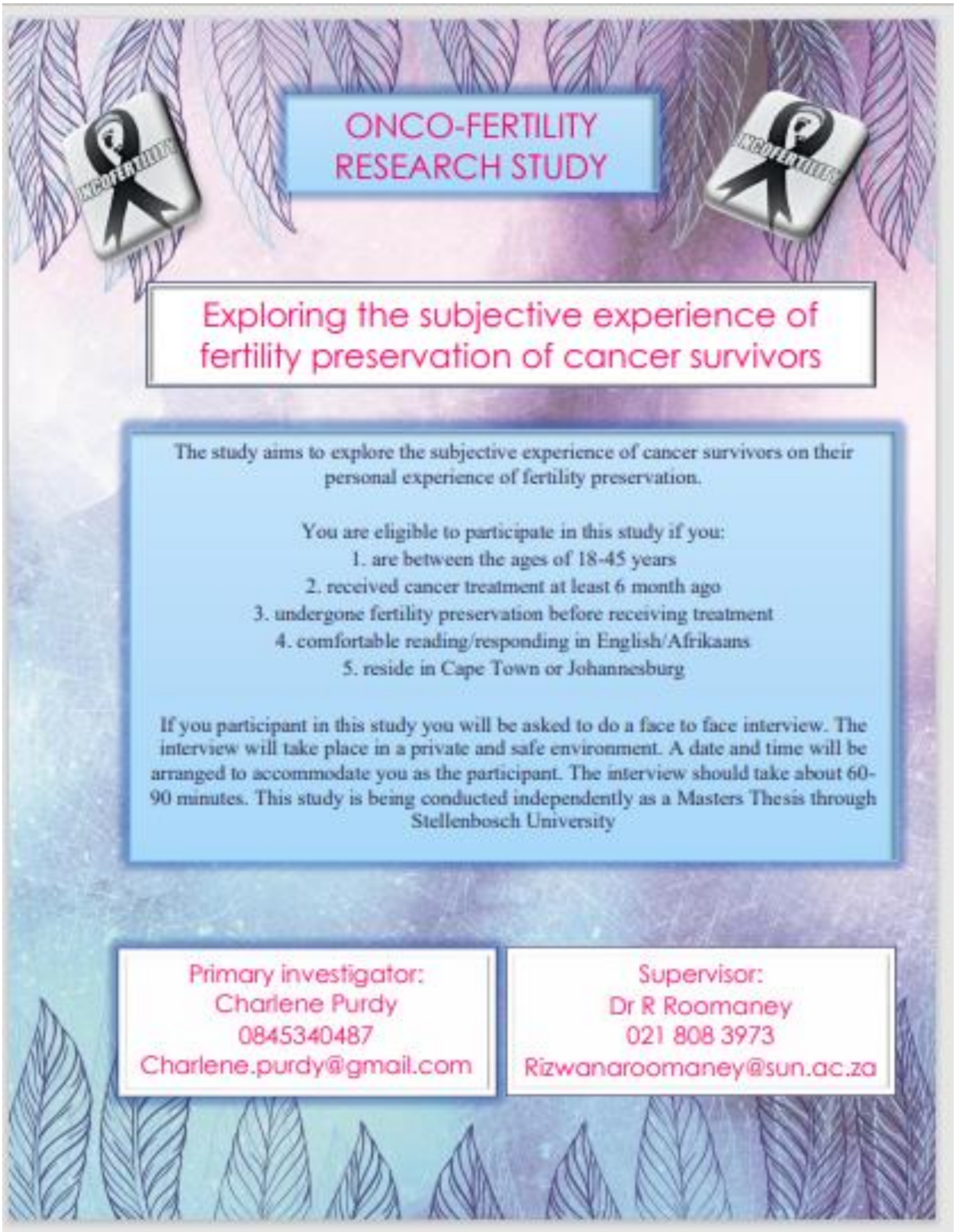
Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number:
IRB0005240 (HREC1)•IRB0005239 (HREC2)

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by the World Medical Association (2013). Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects;the South African *Department of Health (2006). Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa (2nd edition)*; as well as the Department of Health (2015). Ethics in Health Research: Principles, Processes and Structures (2nd edition).

The Health Research Ethics Committee reviews research involving human subjects conducted or supported by the Department of Health and Human Services, or other federal departments or agencies that apply the Federal Policy for the Protection of Human Subjects to such research (United States Code of Federal Regulations Title 45 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services.

Page 1 of 1

Appendix C: Recruitment flyer



ONCO-FERTILITY
RESEARCH STUDY

Exploring the subjective experience of fertility preservation of cancer survivors

The study aims to explore the subjective experience of cancer survivors on their personal experience of fertility preservation.

You are eligible to participate in this study if you:

1. are between the ages of 18-45 years
2. received cancer treatment at least 6 month ago
3. undergone fertility preservation before receiving treatment
4. comfortable reading/responding in English/Afrikaans
5. reside in Cape Town or Johannesburg

If you participant in this study you will be asked to do a face to face interview. The interview will take place in a private and safe environment. A date and time will be arranged to accommodate you as the participant. The interview should take about 60-90 minutes. This study is being conducted independently as a Masters Thesis through Stellenbosch University

Primary investigator:
Charlene Purdy
0845340487
Charlene.purdy@gmail.com

Supervisor:
Dr R Roomaney
021 808 3973
Rizwanaroomaney@sun.ac.za

Appendix D: Interview schedule

Interview Schedule

> Thank you for taking the time to meet with me today and sharing your experience with me

> I look forward to hearing about you experience.

- **Please feel free to answer each question in your own time**
- **If you feel you need to stop, please tell me and we can stop the interview at any time**
- **You don't have to answer any question you don't want to**
- **You only have to say as much as you feel comfortable with**

Demographic

> Clinic?

Name:

Age: Age at time of diagnoses:

Employment:

Children (how many/ages):

Type of cancer:

Diagnosed date:

Stage of cancer:

Type of treatment:

Treatment start date: Treatment end date:

Relationship status: At the time: Currently:

Timeline regarding cancer/ fertility preservation:

(how long did they have to decide for fertility preservation)

Aware of fertility preservation/knowledge of fertility preservation:

(were they aware of fertility preservation before being told about it)

Additional notes:

Questions:

1. Could you tell me about the process of fertility preservation in your own words?

- who was with you.

- who was the first person to tell you about FP

2. Could you tell me more about the thoughts you had before, during and after the process of fertility preservation.

3. Could you tell me about the feelings you had, before, during and after preserving your fertility.

4. Could you tell me about your own personal expectations of motherhood before you were diagnosed with cancer/ after?

-were there any plans for children

5. Could you tell me about your fertility related concerns you had

- relationship? Partner concerns?

6. Could you describe how fertility preservation had an impact on you:
    - physical
    - emotional
    - socially (relationships)

7. Overall could you tell me about the experience of fertility preservation?

8. Is there anything you would have wanted to be done different? (referral) (treatment)

9. Could you tell me if you were aware of any potential risks, if so... what were these?

10. Could you tell me about how did you decide to opt for fertility preservation.

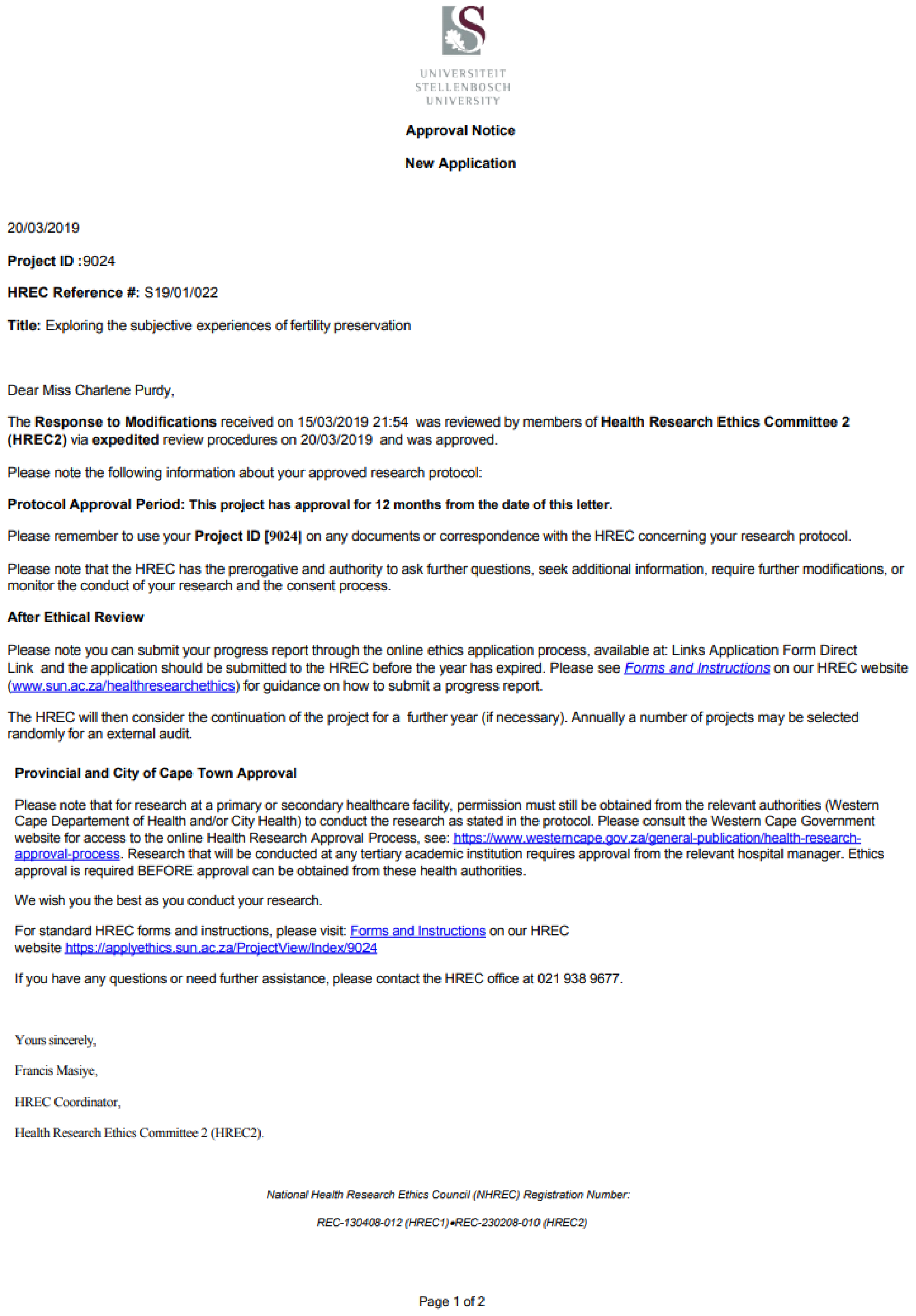
    - who helped you to decide

    - are there any risks that influenced your decision (cost, time , pain)

11. What do you feel you learned about yourself during this process?

> Thank you very much for sharing your experiences with me.

Appendix E: Health and Research Ethics Committee Approval Letter



UNIVERSITEIT
STELLENBOSCH
UNIVERSITY

Approval Notice

New Application

20/03/2019

Project ID :9024

HREC Reference #: S19/01/022

Title: Exploring the subjective experiences of fertility preservation

Dear Miss Charlene Purdy,

The **Response to Modifications** received on 15/03/2019 21:54 was reviewed by members of **Health Research Ethics Committee 2 (HREC2)** via **expedited** review procedures on 20/03/2019 and was approved.

Please note the following information about your approved research protocol:

Protocol Approval Period: This project has approval for 12 months from the date of this letter.

Please remember to use your **Project ID [9024]** on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review

Please note you can submit your progress report through the online ethics application process, available at: Links Application Form Direct Link and the application should be submitted to the HREC before the year has expired. Please see *Forms and Instructions* on our HREC website (www.sun.ac.za/healthresearchethics) for guidance on how to submit a progress report.

The HREC will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility, permission must still be obtained from the relevant authorities (Western Cape Departement of Health and/or City Health) to conduct the research as stated in the protocol. Please consult the Western Cape Government website for access to the online Health Research Approval Process, see: https://www.westerncape.gov.za/general-publication/health-research-approval-process. Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and instructions, please visit: Forms and Instructions on our HREC website https://applyethics.sun.ac.za/ProjectView/Index/9024

If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.

Yours sincerely,

Francis Masiye,

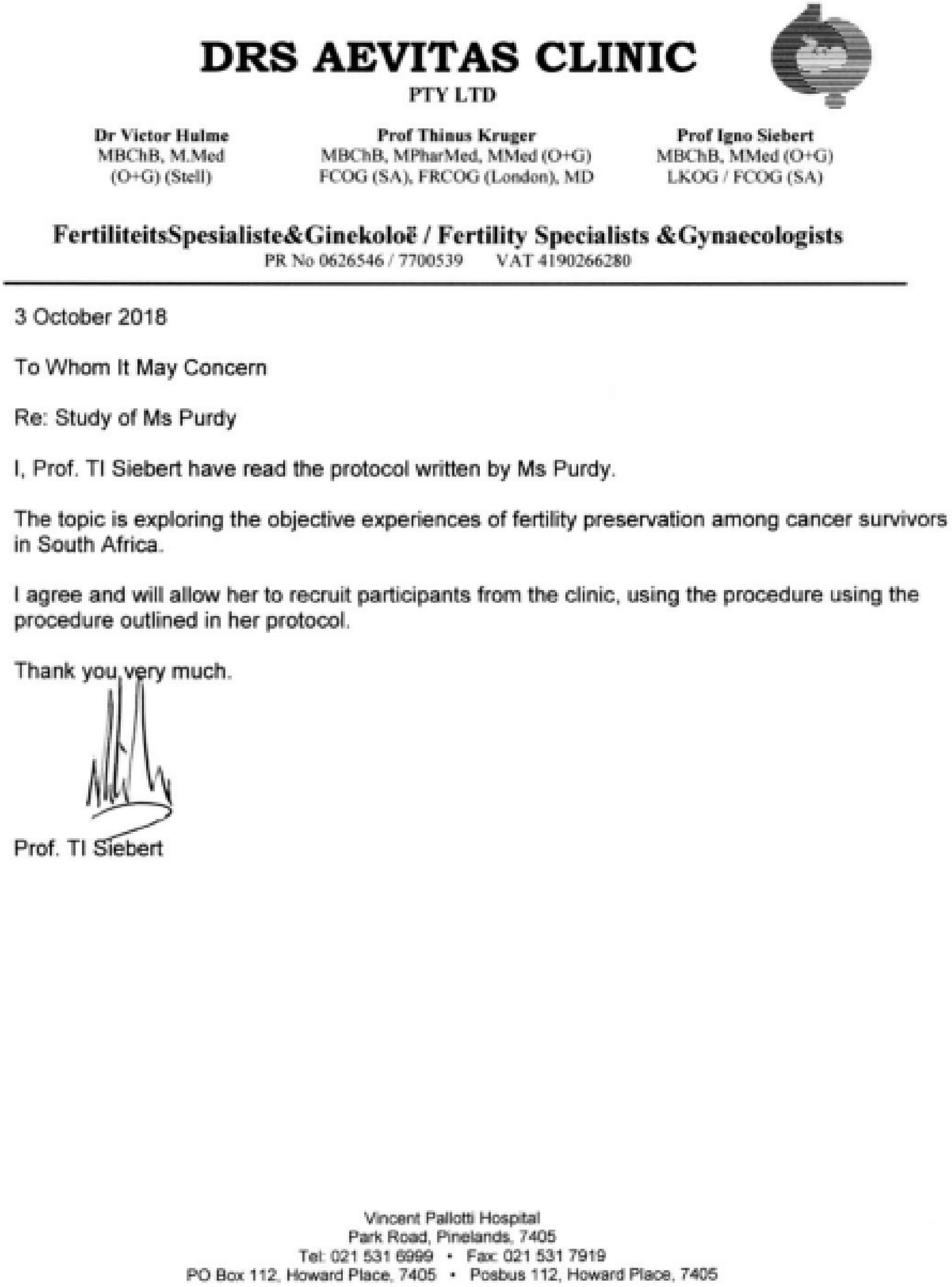
HREC Coordinator,

Health Research Ethics Committee 2 (HREC2).

National Health Research Ethics Council (NHREC) Registration Number:

REC-130408-012 (HREC1)•REC-230208-010 (HREC2)

Appendix F: Fertility clinic approval and support letter



DRS AEVITAS CLINIC
PTY LTD

Dr Victor Hulme
MBChB, M.Med
(O+G) (Stell)

Prof Thinus Kruger
MBChB, MPharMed, MMed (O+G)
FCOG (SA), FRCOG (London), MD

Prof Igno Siebert
MBChB, MMed (O+G)
LKOG / FCOG (SA)

FertiliteitsSpesialiste&Ginekoloë / Fertility Specialists &Gynaecologists
PR No 0626546 / 7700539 VAT 4190266280

3 October 2018

To Whom It May Concern

Re: Study of Ms Purdy

I, Prof. TI Siebert have read the protocol written by Ms Purdy.

The topic is exploring the objective experiences of fertility preservation among cancer survivors in South Africa.

I agree and will allow her to recruit participants from the clinic, using the procedure using the procedure outlined in her protocol.

Thank you very much.

Prof. TI Siebert

Vincent Pallotti Hospital
Park Road, Pinelands, 7405
Tel: 021 531 6999 • Fax: 021 531 7919
PO Box 112, Howard Place, 7405 • Posbus 112, Howard Place, 7405

The Inner Circle, 159 Rivonia Road, Morningside, 2196 | P.O. Box 652837, Benmore, 2010
Tel: (011) 911 4700 or 0861 882522 | Fax: 0865100951
www.vitalab.com | info@vitalab.com

To whom it may concern:

I have read the protocol by Ms. Charlene Purdy titled "Exploring the Subjective Experience Fertility Preservation among Cancer Survivors in South Africa".

Ms. Purdy is conducting this study for an MA Psychology degree at Stellenbosch University under the supervision of Dr Roomaney.

I will allow her to recruit participants from the Clinic, using the procedure outlined in her protocol.

Regards

Dr Chris Venter
Director Vitalab
M.B. Ch.B . F.C.O.G.(S.A.) M.Med.(O & G)

Reproductive Medicine Specialists:
Dr. L. Gobetz, Dr. S. Volschenk, Dr. C. Venter
Reg: 1997/000867/21 Vat: 4560163653 Pr No: 1606417

Dr L Gobetz M.B.,Ch.B., F.C.O.G.(S.A.)
Dr S Volschenk M.B.,Ch.B., F.C.O.G.(S.A.) M.Med.(O & G) (cum laude)
Dr C Venter M.B. Ch.B . F.C.O.G.(S.A.) M.Med.(O & G)
Dr Y Unterslak MBChB (Pret), FCOG (S.A.), MMED (O & G)

Appendix G: Informed consent

TITLE OF THE RESEARCH PROJECT: Exploring the Subjective Experiences of Fertility Preservation Among Afrikaans And English-Speaking Cancer Survivors Within Private Clinic Facilities

REFERENCE NUMBER: S19/01/022

PRINCIPAL INVESTIGATOR: Ms Charlene Purdy (Charlene.purdy@gmail.com)

CONTACT NUMBER: 084 534 0487

SUPERVISOR: Dr RizwanaRoomaney (rizwanaroomaney@sun.ac.za)

ADDRESS: Department of Psychology, Stellenbosch University, RW Wilcocks Building;Ryneveld Street; Stellenbosch, 7600

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary,** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South

African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

- This study will be conducted at four fertility clinics, three within theWestern Cape and one in Johannesburg, where 15-20 participants will be recruited to take part in this study.

- This project aims to explore women's subjective experience of fertility preservation among cancer survivors in South Africa. We would like to discuss your personal subjective experience of undergoing fertility preservation, explore your fertility related thoughts and concerns you had when you were diagnosed with cancer. It is important that you discuss the full process and all it entails, including positive and challenging aspects. In addition, we would like to discuss the factors that played a role in the decision-making process regarding your decision to opt for fertility preservation. Being diagnosed with cancer is a daunting process an individual goes through; however, when their fertility is threatened it becomes a topic that influences a physical, emotional and psychological level. Providing some information on the subjective experience of fertility preservation, will help individuals who are not familiar with the phenomenon or who are currently experiencing something similar.

Why have you been invited to participate?

- You have been invited to participate in this study because you underwent fertility preservation before receiving treatment for your cancer. We are only inviting women who are currently in remission, underwent fertility preservation, between the ages of 18 years and 45 years, and who are able to communicate and understand either English or Afrikaans. You have been invited since you meet the inclusion requirements and have information to share regarding the personal experience of fertility preservation.

What will your responsibilities be?

- Should you choose to participate in the study, you will be requested to avail yourself for an interview and answer questions as honestly as possible. Please feel free to let the interviewer know if you are uncomfortable answering a particular question or would rather end the interview and this will be allowed.

Will you benefit from taking part in this research?

- There are no direct personal benefit expected for you in your participation in this study, however, you may benefit from speaking about your experience. Despite there being no personal benefit for you, the information gathered in this study may benefit future patients who are diagnosed with cancer and who decide to undergo fertility preservation.
- You will receive compensation for time, inconvenience and expenses. You will receive R100 gift voucher for participating and will be reimbursed with R50 for travel expenses, where incurred.

Are there in risks involved in your taking part in this research?

- There are no expected risks involved in you taking part in this study.

Who will have access to your medical records?

- The information that is share with me will be treated as confidential and protected. During and after the study your identity will remain anonymous; no identifying information will be shared in my Master's Thesis or any publication subsequent. The only people who will have access to your information will be I as the primary investigator (Charlene Purdy) and my supervisor (Dr RizwanaRoomaney).

What will happen in the unlikely event of some form injury occurring as a direct result of your taking part in this research study?

- The participant is at no risk of any physical harm during this study as it only a interview that will be taking place thus placing no potential physical injury to the participant. If participant expresses any emotional distress during the interview, they will be referred to counselling services at The South African Depression and Anxiety Group located in Cape Town.
  Tel: 0800 12 13 14 Email:zane@sadag.org

Will you be paid to take part in this study and are there any costs involved?

- No, you will not be paid to take part in the study, but your transport will be compensated as mentioned above.

Is there anything else that you should know or do?

- You can contact Charlene Purdy at 084 534 0487 if you have any further queries or encounter any problems.
- You can contact Dr Rizwana Roomaney at 021 808 3973 if you have any further queries or encounter any problems.
- You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor.
- You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I ………………………………..…………. agree to take

part in a research study entitled **Exploring the Subjective Experiences of**

Fertility Preservation Among Afrikaans And English-Speaking Cancer

Survivors Within Private Clinic Facilities.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ....…........……………….. on (*date*) …………....…2020

....

Signature of participant **Signature of witness**

Declaration by investigator

I *(name)* ……………………………………………..……… declare that:

- I explained the information in this document to …………………………………..
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use a interpreter. (*If a interpreter is used then the interpreter must sign the declaration below.*

Signed at (*place*) ....…........……………….. on (*date*) …………...……….. 2020

....

Signature of investigator **Signature of witness**

Appendix H: Project extension approval letter

UNIVERSITEIT
STELLENBOSCH
UNIVERSITY

Approval Letter
Progress Report

16/03/2020

Project ID: 9024

Ethics Reference No: S19/01/022

Project Title: Exploring the subjective experiences of fertility preservation

Dear Miss Charlene Purdy

We refer to your request for an extension/annual renewal of ethics approval dated 09/03/2020.

The Health Research Ethics Committee reviewed and approved the annual progress report through an expedited review process.

The approval of this project is extended for a further year.

Approval date: 16 March 2020

Expiry date: 15 March 2021

Kindly be reminded to submit progress reports two (2) months before expiry date.

Where to submit any documentation

Kindly note that the HREC uses an electronic ethics review management system, *Infonetica*, to manage ethics applications and ethics review process. To submit any documentation to HREC, please click on the following link: https://applyethics.sun.ac.za.

Please remember to use your Project Id 9024 and ethics reference number S19/01/022 on any documents or correspondence with the HREC concerning your research protocol.

Yours sincerely,

Mrs. Brightness Nxumalo
Coordinator: Health Research Ethics Committee 2

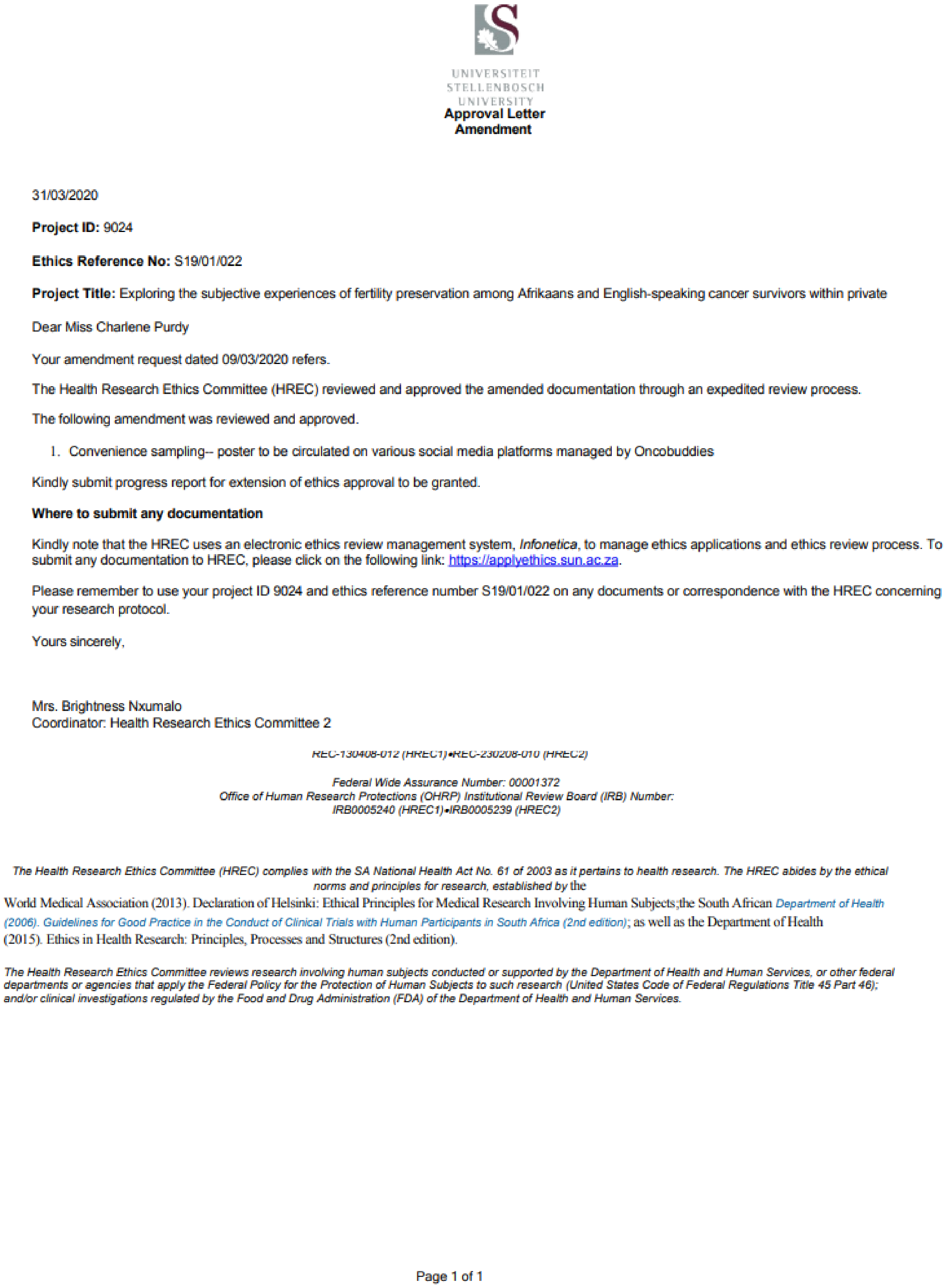
National Health Research Ethics Council (NHREC) Registration Number:
REC-130408-012 (HREC1)•REC-230208-010 (HREC2)

Federal Wide Assurance Number: 00001372
Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number:
IRB0005240 (HREC1)•IRB0005239 (HREC2)

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by the World Medical Association (2013). Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects; the South African Department of Health (2006).Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa (2nd edition); as well as the Department of Health (2015). Ethics in Health Research: Principles, Processes and Structures (2nd edition).

The Health Research Ethics Committee reviews research involving human subjects conducted or supported by the Department of Health and Human Services, or other federal departments or agencies that apply the Federal Policy for the Protection of Human Subjects to such research (United States Code of Federal Regulations Title 45 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services.

Appendix I: Ammendement to sampling procedure



UNIVERSITEIT
STELLENBOSCH
UNIVERSITY

Approval Letter
Amendment

31/03/2020

Project ID: 9024

Ethics Reference No: S19/01/022

Project Title: Exploring the subjective experiences of fertility preservation among Afrikaans and English-speaking cancer survivors within private

Dear Miss Charlene Purdy

Your amendment request dated 09/03/2020 refers.

The Health Research Ethics Committee (HREC) reviewed and approved the amended documentation through an expedited review process.

The following amendment was reviewed and approved.

1. Convenience sampling-- poster to be circulated on various social media platforms managed by Oncobuddies

Kindly submit progress report for extension of ethics approval to be granted.

Where to submit any documentation

Kindly note that the HREC uses an electronic ethics review management system, *Infonetica*, to manage ethics applications and ethics review process. To submit any documentation to HREC, please click on the following link: https://applyethics.sun.ac.za.

Please remember to use your project ID 9024 and ethics reference number S19/01/022 on any documents or correspondence with the HREC concerning your research protocol.

Yours sincerely,

Mrs. Brightness Nxumalo
Coordinator: Health Research Ethics Committee 2

REC-130408-012 (HREC1)•REC-230208-010 (HREC2)

Federal Wide Assurance Number: 00001372
Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number:
IRB0005240 (HREC1)•IRB0005239 (HREC2)

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by the World Medical Association (2013). Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects;the South African *Department of Health (2006). Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa (2nd edition)*; as well as the Department of Health (2015). Ethics in Health Research: Principles, Processes and Structures (2nd edition).

The Health Research Ethics Committee reviews research involving human subjects conducted or supported by the Department of Health and Human Services, or other federal departments or agencies that apply the Federal Policy for the Protection of Human Subjects to such research (United States Code of Federal Regulations Title 45 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services.

Appendix J: Defining cancer stages

Although there are different types of staging for different cancers, oncologists most commonly use the number system in which five cancer stages are identified (Chavan, 2013):

Stage 0 – Cancer cells that are still in the location where they started and have not spread.

Stage 1 – Localized cancer that has spread into nearby tissues. It has not yet spread to lymph nodes or other areas.

Stage 2 – Cancer has spread to a regional area or into nearby tissues or lymph nodes.

Stage 3 – More advanced regional spread than Stage 2.

Stage 4 – Cancer has spread to distant parts of the body. This stage is often referred to as metastatic cancer, or a cancer that has spread to other areas of the body.