

Involuntary childlessness: An interpretive phenomenological inquiry into couples' experiences of infertility treatment in the South African public health sector

by

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DECLARATION

I, Adele Wybourn, declare that this thesis with the title "**Involuntary childlessness: An interpretive phenomenological inquiry into couples' experiences of infertility treatment in the South African public health sector**" is my original work except where I used or quoted another source, which has been acknowledged. I further declare that the work I am submitting has never been submitted before for another degree to any other university or tertiary institution for examination.

Signature:

Date:

30 April 2017



Involuntary childlessness: An interpretive phenomenological inquiry into couples' experiences of infertility treatment in the South African public health sector

Involuntary childlessness presents an array of far reaching challenges for couples who reside in pronatalistic developing countries. Whilst the literature recognises the diverse difficulties that infertility can present, South African research that centres on the couple system's experiences of fertility treatment is scant and dated. The goal of my study was to closely explore couples' joint fertility treatment experiences by providing an opportunity for couples to share their experiences and at the same time for them to make sense of their fertility treatment experiences, the results of which were utilised to establish guidelines for healthcare professionals working in this context. The Reproductive and Endocrine Unit (REU) at the Steve Biko Academic Hospital (SBAH) provided the public healthcare context for sourcing participants for this study. Embracing an Interpretative Phenomenological Analysis (IPA) approach afforded me the opportunity to conduct semi-structured interviews with eight couples over an eight-month period, analysis of which assisted me in gaining an in-depth, experience-near understanding of couples' joint fertility treatment experiences.

The main findings:

Participants' drew on their experiences of private and public healthcare fertility treatment as well as their interpersonal, social, amd spiritual contextual experiences in making sense of their fertility treatment experiences in the public health sector. Couples' private healthcare experiences were shaped by the unaffordablity and overall disappointment in this treatment option while their public healthcare treatment encounters in contrast were shaped by comprehensive, conversational, informative and facilitative service experiences.

Transcending the boundaries of participants' contextual treatment experiences, couples portrayed their experiences as being further shaped by their interpersonal experiences of their partner as well as their joint coupleship experiences during treatment. Couples experienced treatment as an all-consuming, intrusive process, invading their time, space and thoughts. Although four of the eight couples terminated their fertility treatment due to their inability to financially sustain it, participants shared that the challenges of fertility treatment extended beyond the boundaries of affordability, as it introduced the treated body as a problematic



adjunct to their couple relationship. The emotional processes sketched by the couples were etched with emotional highs and lows, which required couples to cope and activate coping strategies in the face of the treatment challenges they faced. Furthermore, couples expressed how their social contexts such as family, friendships, work, community and spirituality shaped their treatment experiences in intricate ways and how this either enabled or inhibited couples to cope during their treatment processes. Taken as a whole, the findings of my study portray fertility treatment experiences as a process rather than a single event (or series of events), which requires the couple to adjust.

The implications of these findings are that in planning interventions with couples receiving treatment, healthcare practitioners should consider integrating bio-psycho-social-spiritual elements into the supportive work they do with couples who are receiving fertility treatment.



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Together you have supported me through this process and remained curious and in so doing, you have made it an interactive one, which I have really enjoyed. Thank you for supporting and encouraging me always. They say it takes a village to raise a child, and at times I needed a village to get this PhD done. Thank you for being a pivotal part of that for me.

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Abbreviation	Description	Chapter	Page
ART	Assisted Reproductive Technology	Chapter 1	9
AI	Artificial Insemination	Chapter 2	44
BMI	Body Mass Index	Chapter 2	37
DI	Donor Insemination	Chapter 2	45
DNA	Deoxyribonucleic Acid	Chapter 2	37
FGM	Female Genital Mutilation	Chapter 2	39
FSH	Follicle-stimulating Hormone	Chapter 2	38
GP	General Practitioner	Chapter 2	42
HO	Hospital 0	Chapter 1	10
H1	Hospital 1	Chapter 1	10
H2	Hospital 2	Chapter 1	10
Н3	Hospital 3	Chapter 1	10
HIV/AIDS	Human Immunodeficiency Virus/ Acquired	Chapter 2	30
ICSI	Intra-cytoplasm Sperm Injection	Chapter 1	10
ICMART	International Committee for Monitoring Assisted	Chapter 2	28
IPA	Interpretive Phenomenological Analysis	Chapter 4	104
IUI	Intrauterine Insemination	Chapter 1	10
IVF	In-Vitro Fertilisation	Chapter 1	10
NHS	National Health Service	Chapter 2	31
PCOS	Polycystic Ovary Syndrome	Chapter 2	32
REU	Reproductive and Endocrine Unit	Chapter 1	9
SA	South Africa	Chapter 3	66
SBAH	Steve Biko Academic Hospital	Chapter 1	9
STIs	Sexually Transmitted Infections	Chapter 2	30
UK	United Kingdom	Chapter 2	31
WHO	World Health Organization	Chapter 2	27
USA	United States of America	Chapter 3	62
UP	University of Pretoria	Chapter 4	109

List of Abbreviations



PART A



PROLOGUE

Them

Where was he? It was 14:45 on a Friday afternoon, a time they had been given over three months ago, and he was not there yet. Pacing nervously up and down the ramp to the entrance of the fertility clinic, she waited, and waited and waited for what seemed like forever and two minutes before 3pm, he arrived. Finally! Breathing a quivering sigh of relief, they clasped hands and walked in nervously together. It was at that very moment, and not a moment earlier, that she accepted that her body was broken.

Three years prior to their appointment at the fertility clinic, the couple began trying for a baby, this after eight years of being voluntarily, self-proclaimed "non-multipliers". For them, they enjoyed their life as a young couple, travelling and exploring new countries together and had little desire for growing their family beyond their couple relationship. That was until they went on holiday in 2006. Something changed for them there where the idea of having children became something they now envisaged. So, if you want a baby, you try and a few months later, voila! Or, so they thought. After 12 long moths of trying, irregular cycles, and disappointment that began to sink in deeper and deeper from around the sixth month, they sought assistance. She went off to the gynaecologist, highlighting to him the issues that she had file-saved over the past year, and explained their situation to him in detail. Following his advice, nothing seemed to work. Another ten months passed, where disappointment seemed to seep deeper and deeper with the passing of each unsuccessful month. She prepared herself every month: "this time...this time I will not get disappointed if it's negative!", to two months later feeling that "you can't be more disappointed than 'disappointed', so it is okay to hope...", to feeling like "I am completely broken".

Her invisible disability was made noticeable when people asked about their childlessness. Her physical brokenness was revealed in those moments to a world that medicated her despondence with advice such as "stop trying and it will happen". For both of them, it now became a problem, a very painful, ever growing problem; one which she felt ultimately responsible for. Her body told her that something was wrong with her, and that this was the reason for them not falling pregnant. While her husband told her that it was something that they both experienced, she could not help feeling responsible for their reproductive disability. They



spoke a lot about it as they did about everything else and decided to seek help from reproductive specialists. Ironically, the contact details were given to her by someone she had met at a baby shower. By that time, she could hardly look at a pregnant woman without the appearance of the green-eyed monster. And so, she decided from there to make an appointment.

As they clasped hands on that Friday afternoon and walked in to the clinic, she felt a sense of overwhelming embarrassment. Where had this feeling come from? Waiting for their treating doctor was exposing. Everyone in that waiting room knew why they were there and everyone had the same goal in mind: to have a baby. Burying her head behind a magazine that she did not read, was the moment she asked herself: "How are other couples experiencing coming to a fertility clinic?" Following months of failed fertility treatments, that were emotionally and physically painful, they finally got the news that they were expecting a baby. Although delighted that their fertility treatment experiences.

Fifteen months later, once they had come full circle in their treatment, she thought about exploring her curiosity about couples' treatment experiences more formally. So, she did and here I am.



CHAPTER 1: INTRODUCTION Encountering Infertility

I think with my heart and I move with my head I open my mouth and it's something I've read I stood at this door before, I'm told... Confused what I thought with something I felt Confused what I feel with something that's real Come with me now... I'm gonna show you how...

"Come with me now" (Kongos, 2012, track 1).¹

¹ Lyrically this song asks the listener to accompany the vocalist as he tells his story. A story I connect with personally. I ask the same of the reader here, as I take you through the meandering paths of this study.



Introduction

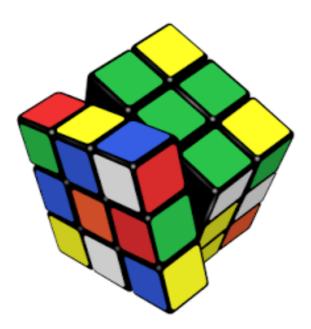


Figure 1: Photograph of a Rubik's Cube (Rubik's Cube, n.d.).

Since the earliest days of the Rubik's Cube, mathematicians and scientists have been attempting to calculate the minimum number of moves needed to complete it (Kunkle & Cooperman, 2007). Ernő Rubik, Hungarian sculptor and professor of architecture, was responsible for its invention in 1974, but it was not until the early 1980's that it became a phenomenon (Kunkle & Cooperman, 2007; Rubik, 1983). Since then teams of researchers have processed every one of the Rubik's Cube's 43,252,003,274,489,856,000 different configurations to work out what the maximum number of moves would be to complete it (Rokicki, 2014). As it stands, an Australian by the name of Feliks Zemdegs, is the current world Rubik's Cube champion, with a 6.34-second solving time (World Cube Association, 2016). What makes this 1980's cube the phenomenon it so obviously still is all these years later? For me, it is in its possibilities, complexities and challenges. Neatly and colourfully packaged in this multi-rotating, three-dimensional cube, are a surprisingly impossible number of possibilities. These possibilities lie in the potential configurations, the number of steps and solving time required to complete a Rubik's Cube. At face value, I would not think that this neatly packaged plastic cube would attract so much interest. But here we are, 37 years later, and scientists are still trying to understand the marvel that encapsulates it.



A quirky coincidence that here I am, 37 years later, and I too am equally intrigued by an enormously intricate phenomenon, which at first seemed neatly packaged in a seemingly self-contained box labelled: "infertility". From the moment I began exploring infertility, and more closely, people's experiences of infertility treatment, the more I became aware of the intricacies and possibilities of experiences which captured my attention, in much the same way I would imagine the scientists I spoke of earlier.

The more I researched aspects of involuntary childlessness, the more intrigued I became with what I read and with that, the more I realised the breadth of interest and research activity displayed across differing disciplines. I consider the intricacies and possibilities in respect of fertility treatment experiences as exponential; much like the unassuming Rubik's Cube is surprisingly complex. As it applies to my study, the reader is introduced to the experiences of involuntarily childless couples who reside in South Africa and their fertility treatment experiences in the public healthcare context.

This, the first of seven chapters, equips the reader with a compass to navigate this research project. I set off by sketching the (i) research problem, providing a focused introduction to the aspect of infertility I became most curious about: fertility treatment experience. The discussion transitions from there to the (ii) research question, which informed and guided the entire research process. Against the backdrop of the research problem and the research question, the reader explores the (iii) setting of this study, which finds itself submerged in a larger developing world milieu. Thereafter, I explore the (iv) aims, the motivation for and the goals of this research project, highlighting the (v) research design and methods, and concluding the chapter with an outline of the (vi) structure of this study.

I introduce the reader to the research problem first, followed by the question underpinning this research project, before contextualising my study.

Research Problem

I want to portray the research problem of this study by means of an image, followed by a summary of its story. My hope is that the reader will take a moment to look closely at it, reflecting on the responses it evokes in you.





Figure 2: Female baby encircled with syringes used during her mother's IVF treatment (Sher Institute, 2015).

A poignant photograph of a baby girl, encircled by hundreds of syringes arranged in a heart shape, stands here as an impactful depiction of the pain and joy of one woman's fertility treatment experience. This powerful image reflects, without saying one word, the lengths people may go to, to realise their dream of parenthood and highlights the sometimes long and arduous process that so many other couples can connect with (Brown, 2015).

The mom who took this photograph, who referred to herself as "Angela", wanted the picture to be shared to motivate couples who are undergoing fertility treatment (Brown, 2015). In the article, she shared that the "needles were the easy part" explaining that "it was the emotional struggle, the ups and downs, that really took a toll." Angela's photo went viral on 8 October 2015, being shared thousands of times over, accompanied with people's own personal comments and shared experiences of fertility treatment. People took to utilising different social media platforms to circulate the photograph and their shared experiences, such as blogs, forums, Facebook pages, and other online platforms (Brown, 2015). Her visual account provides a small glimpse into the aspects that may shape couples' fertility treatment experiences. The photograph and story above, as impactful as it is, shares a woman's story of fertility treatment in a developed country. What then does the developing world's fertility treatment picture look like?



My curiosity regarding South African couples' fertility treatment experiences began long before I encountered this photograph, although the photograph came at an opportune time in this research process. Firstly, it is coincidental that the image circulated when it did because it was an external reminder which solidified for me the importance of this project. Secondly, the photograph resonated with me beyond what may be perceived as obvious (i.e. it represented a research interest of mine). It was more than that; at the time I saw the picture, I had concluded the data collection and was in the midst of writing up. As I wrote, the photograph became a visual cue that reminded me that I was writing the storyboards of eight South African couples' fertility treatment experiences. My task as I saw it was to allow the participants' stories to be told as vividly in words as the photograph had told the story of Angela's treatment experiences. I had many questions as I wondered how couples' joint treatment experiences would be narrated in the end and what they would isolate as meaningful aspects of their fertility treatment experiences in the South African public health context. My intention in undertaking this project was to gain insight into an under-researched aspect of infertility in the developing world context: couples' experiences of fertility treatment.

The literature depicts involuntary childlessness as a multidimensional health issue, which has the potential to significantly impact the individual and couple system (Daly & Bewley, 2013; Saridi & Georgiadi, 2010). One in six couples experience infertility, with the largest proportion living in developing countries, where Africa reportedly has the highest global incidence of infertility (Ombelet & Campo, 2007; Salhan, 2011; Sharma, Mittal, & Aggarwal, 2009). The dilemma presented here is that the pronatalistic values associated with some cultures are at odds with involuntary childlessness, having far-reaching cultural, individual, economic and social consequences. Couples living in resource-poor communities face difficulties when it comes to the availability of, and access to, fertility treatment, further compounding their infertility experiences (Bambra, 1999; Hammarberg & Kirkman, 2013; Ombelet & Campo, 2007; Salhan, 2011; Sharma, Mittal, & Aggarwal, 2009; Van der Spuy, 2009). Whilst the literature acknowledges the diverse challenges that involuntary childlessness presents, research that centres on the couple system's experience of fertility treatment in the public health sector is scant and dated and, therefore, requires current exploration (Botha, 1985; Gravett, 2009; Sundby, Mboge, & Sonko, 1998).

South African research has by and large neglected enquiryinto couples' joint experiences of fertility treatment. This is baffling. Whilst male and female experiences of treatment give



clues as to how the couple system may experience treatment, there are very few studies that target couples' experiences per se, which to me, has treatment implications for healthcare professionals working in the fertility treatment context (Botha, 1985; Gravett, 2009). How do we then support and manage what we do not understand?

As it applies to my research project, my interest lay in accessing South African couples' subjective experiences of fertility treatment in the public health sector to broaden healthcare professionals' knowledge on the topic, so that the best possible care can be provided. In comparison to Angela's stylised photograph above, what you will find as you read through this and other chapters, is the raw, stripped-downaccount of my journey as I attempted to gain insight into South African couples' experiences of fertility treatment in the public health context.

An exposé of the setting of the project is preceded by the research question which guided the project from beginning to end.

Research Question

The aim of my study was to answer the following research question:

"How do couples who have been diagnosed with primary infertility make sense of their experiences of fertility treatment within the South African public health sector?"

To answer this question, I engaged with a fertility unit situated within a public health facility whose staff graciously allowed me to have access to couples who met the inclusion criteria for the project. I provide the background to the unit below before explaining the motivation and goals for this research project.

Setting

South Africa saw the advent of two tertiary Assisted Reproductive Technology (ART) institutions in 1982. The first of its kind in South Africa was set up in Pretoria, and the other in Cape Town (Fourie, Botes, & Van der Merwe, 1988; Kruger et al., 1985). The Steve Biko Academic Hospital (SBAH) formerly known as HF Verwoerd Hospital, houses the Reproductive and Endocrine Unit (REU), which is part of the Department of Obstetrics and Gynaecology at the University of Pretoria. The REU provides diagnostic and ART services and



is also an accredited training unit for clinical technologists and medical biological scientists in Reproductive Biology (see Appendix A for the REU's staff structure) (Huyser & Boyd, 2013).

The REU in SBAH provides diagnostic and ART services to a diverse patient population, the majority of which are from lower- to middle-income groups, with an average gross household income of R16 705.45 per month (Huyser & Boyd, 2013). Administrative categorisation aids the Unit in calculating patient contributions for services rendered. Patients are classified as follows: Hospital 0 (H0) includes those who cannot afford to pay for treatment. On the face of it, they should qualify for free treatment, but a minimum tariff is required by the Unit for services rendered. Hospital 1 (H1) patients earn less that R50 000 per annum and are asked to pay a tariff of R30. Hospital 2 (H2) patients earn less than R72 000 and have a combined household income of less than R100 000 per annum. These patients would be asked to pay a tariff of R86. Hospital 3 (H3) patients are those whose income is greater or equal to R72 000 per annum with a household income equal to or greater than R100 000 per annum. Annual earnings that exceed R100 000 places a patient in the "private patient" category, where the tariff increases to R175. Three types of payment methods are identified: private medical aid, private patients and private foreigners. Private medical aid patients can claim from their medical aids, while the other private patients are liable for the costs.

For administrative purposes, there are two different cost groupings for ART: One being state-subsidised and the other being private patient structured. Another option can be accessed by either category, which is a low-cost option, sub-divided into three low-cost categories. The subsidised category is a low-cost option which is available to couples who do not have medical aid and who have an annual income of less than R50000.00. This option is subject to budget allocation, with only a small number of people qualifying for this category per annum. Patients' who do qualify, must pay registration fees, medication costs and partial media costs. The procedure cost is approximately R1153.33 for an Intrauterine Insemination (IUI) andR15088.41 for In-Vitro Fertilisation (IVF) and Intra-cytoplasm Sperm Injection (ICSI). The private category option is available for couples with a medical aid and/or a household income above R99994.90. An IUI attempt utilising this option can cost up to R5172.15 and a maximum of R21758.70 for IVF/ICSI procedures. The third category is an affordable low-cost option for IVF/ICSI, which is available to patients from categories A and B, based on proposals for accessibleIVF (Ombelet & Campo, 2007; Ombelet, Cooke, Dyer, Serour, & Devroey, 2008). The low-cost option includes medication, minimal clinical, pathology and laboratory fees.



Costs range from R4767.89 to R11438.18 for an IVF/ICSI cycle. Those who wish to select the low-cost treatment option must comply with specific criteria, which are based on aetiology, age and their unique case history (Huyser & Boyd, 2013).

When attempting to compare how public-sector ART treatment costs fair against private sector treatment fees, Huyser and Boyd (2013) enquired at various private sector treatment facilities, and obtained treatment costs for IUI, IVF and ICSI procedures. The estimates included medications, ultrasound scans and laboratory fees. In the private sector, it was estimated that an IVF procedure could cost around R38701.95, ICSI estimated at R39260.78 and an IUI procedure could cost approximately R6444.38. Dyer and Kruger (2012) refer to a standard IVF cycle of R9999.49 (subsidised in the public sector) compared to R35004.16 (private sector) in South Africa. This demonstrates that public sector ART facilities provide more affordable treatment options, but as with most things, there are "T's & C's", which are pre-determined by the couple's financial situation and their case history.

Huyser and Boyd (2012) demonstrate where most fees are allocated when undergoing private IVF treatment in South Africa: 8% of costs are allotted to clinic fees, 28% for medication, 29% for clinician fees and consultation costs, and 35% for laboratory fees (this includes use of equipment and laboratory, disposables, culture media and staff). This is in comparison to 39.2% of total IVF cycle cost at the fertility unit at SBAH. Items used in the laboratory for an ICSI cycle can amount to 48% of the costs per ICSI cycle.

The dichotomy as it presents itself to me is this: There are currently public fertility treatment options available to the South African population. These options cost the very facilities providing the services money; a large amount of which goes into running costs. The REU at SBAH is entirely dependent on public funding and therefore cannot provide a service without a minimum tariff principle being implemented. This makes it possible for the REU to provide the services it says it can, but makes it difficult for those from impoverished communities to access and utilise the services offered. The current impetus echoed in the works of Ombelet and Campo (2007) and Ombelet et al. (2008) is that it is imperative to provide affordable ART options in developing countries, which the staff at the REU echoes and they are working hard to do just that. However, the REU cannot run on passion alone and does require funding, which affects the pockets of those accessing the facility, irrespective of classification.



When we review the aforementioned calculated costs for different ART treatment options, it is evident that for lower income earners it can be near impossible to complete treatment when research conducted by Huyser and Boyd (2012) demonstrates that those who are in the financial position to complete ART treatment earn between R11 500 to R16 700 per month. What does this mean for H0, H1 and H2 patients? How does this impact their accessibility to these and other treatment options in South Africa? Even though we have a public/tertiary unit dedicated to providing accessible and affordable fertility services to the public at a fraction of the cost that private facilities offer, it still seems that it is largely a costly process for both the service providers and the patients. Every cent has an allocated place.

This study finds itself immersed in the folds of a developing African country. The financial context of the couples who wish to access and utilise services offered by the REU at SBAH in the hopes of having their own success story cannot be ignored and speaks to an important aspect of the fertility Rubik's Cube in Southern Africa. The narratives shared by research participants in this study revealed that the quest for a happy ending comes with a price tag and for some, this in itself meant the postponement or the end of their pursuit to finding answers and eventual success.

Against the backdrop of the research setting, I now delineate the motivation and goals for this research project.

Motivation

The motivation for initiating this research project was twofold: Firstly, although the issue of infertility has been, and continues to be, widely researched across disciplines (see Chapter 2 and Chapter 3 literature reviews), a gap is present in the developing world literature as it relates to the couple system's experience of fertility treatment. Secondly, and a follow-on from the former, this study was professionally motivated in that the research aimed to propose working guidelines for healthcare professionals based on the research findings of this project. I attend to the research motivation first, followed by a discussion of the professional motivations for this research project.

Research Motivation

The pervasive literature trend, both internationally and locally, presents a dichotomous focus on either women's or men's experiences of infertility in isolation, with very few studies



focusing on couples' subjective experiences of treatment (Dyer, Abrahams, Mokoena, & Van der Spuy, 2004; Dyer, Mokoena, Maritz, & Van der Spuy, 2008). My research project attempts to begin to bridge the gap in the literature by researching the couple system's experience of fertility treatment, regardless of who had the fertility issue. I viewed the couple as receiving the fertility treatment and their subjective experiences of fertility treatment were the core focus of this research.

From a methodological perspective, there has been very limited qualitative research conducted on the experience of infertility and in particular, the experience of fertility treatment in South Africa (Dyer, Mokoena, Maritz, & Van der Spuy, 2008; Kantor, 2006). The majority of studies have been quantitative in nature (Anderson, Sharp, Rattray, & Irvine, 2003; Dyer, Abrahams, Hoffman, & Van der Spuy, 2002; Dyer, Abrahams, Mokoena, & Van der Spuy, 2002; Dyer, Abrahams, Mokoena, & Van der Spuy, 2004; Dyer, Abrahams, Mokoena, Lombard, & Van der Spuy, 2005; Dyer, Lombard, & Van der Spuy, 2009; Dyer, Mokoena, Maritz, & Van der Spuy, 2008). Therefore, I intended to make a qualitative contribution to the psychological field through employing a methodology that has not been utilised in South African infertility research to date, i.e. Interpretative Phenomenological Analysis (IPA). I applied an IPA methodology to my data collection, analysis and reporting on the research findings, which I believe is a novel contribution to South African psychological literature.

The drive to undertake this research project was not only propelled by a lack of current South African literature on the topic, but was also professionally driven, as my hopes were that additional insights obtained from the research findings would lead to the provision of improved and well-informed treatment of those who are undergoing fertility treatment.

Professional Motivation

My hopes at the outset of this project were that my research findings would not only contribute to current literature, but that the findings could also be transferrable to a professional context. I envisaged healthcare professionals as being able to translate and apply the research findings when developing supportive interventions for both men and women in their own capacities, as well as the treatment of the couple as a system. The outcomes of the research were written in a manner that would easily assist practitioners in their application of the findings as they engaged in a supportive role when working with their clients during fertility treatment. Insightful treatment was a key motivating factor in undertaking this project.



Research and professional motivations for undertaking this research project were guided by specific goals I wished to achieve in pursuing this research. I discuss the primary and secondary goals for this project below.

Goals

As I conceptualised this research project, I reflected on how I would translate the motivation for this project into action. In this regard, I set out primary and secondary goals for the project. The primary goal I wanted to achieve was to (i) understand couples' joint fertility treatment experiences. The secondary goals of this project that would assist in actualising the primary goal were (ii) to provide an opportunity for couples to share their experiences and at the same time (iii) for couples to make sense of their fertility treatment experiences; the results of which would be utilised (iv) to establish guidelines for healthcare professionals working in this context.

I refer to the primary goal, leading into a discussion of the secondary goals of this research project.

Primary Goal

The primary goal of this study was to understand couples' joint fertility treatment experiences. This research project sought to understand how couples who have been medically diagnosed with primary infertility make sense of their fertility treatment experiences within the South African public health sector, with the view of establishing guidelines for healthcare professionals working within this context. Thus, the primary goal was to focus on the couple system's experience of fertility treatment.

In order for the primary goal to be achieved, it required the attainment of additional secondary goals.

Secondary Goals

My research primarily sought to understand couples' joint fertility treatment experiences. To create an opportunity to achieve this, the secondary research goals were to (i) afford couples who were experiencing infertility a time and place to share their fertility treatment experiences with me so that I could (ii) gain an understanding of how couples who are experiencing infertility make sense of their fertility treatment, which could then (iii) have implications for practice based on the research findings.



The motivation for and goals of research are the foundations for any research project. However, the execution of a project requires action that is congruent both in design and method for it to come together harmoniously. I briefly discuss the research design and method below before concluding the chapter by explaining the structure of my thesis.

Research Design and Method

To authentically answer the research question, it was important for me to enter the participants' context to better understand their experiences from their point of view (Morris, Leung, Ames, & Lickel, 1999). This meant that I could not adopt a distantiatedetic research position, but rather, as I considered the subjective nature of couples' fertility treatment experiences, the clearer it became that this study would fall within a qualitative research domain. Qualitative research explores subjective, lived experiences, thrusting the researcher out of a controlled laboratory environment into the very context of the phenomenon being explored (Creswell & Clark,2011). Furthermore, qualitative research engages in exploring, describing and interpreting personal experiences of participants (Smith, 2004).

Whilst there are a vast array of qualitative research designs that researchers can choose from such as IPA and narrative psychology, to discourse analysis and focus groups to name but a few, I selected IPA as I believed that this methodology would afford me the opportunity to gain in-depth, experience-near understanding of South African couples' joint fertility treatment experiences. In addition, IPA explores in detail how individuals make sense of their experiences (Smith & Osborn, 2003). Therefore, to best answer the research question, I selected IPA due to its commitment to the detailed exploration of subjective experience and because of the methods it employs in order to achieve this aim (Biggerstaff & Thompson, 2008; Lawler, 1998; Lopez, 2004; Mackey, 2005; Smith, 2010; Smith & Osborn, 2003). IPA is explorative and interpretative in nature and the purpose of my study was to ascertain how couples diagnosed with primary infertility made sense of their fertility treatment experiences (Smith & Osborn, 2003). To achieve this aim, data was collected through in-depth interviews of eight couples over an eight-month period. After I transcribed the interviews, themes were identified. The purpose was not to generalise these findings to the larger population, but to contribute to an understanding of how South African couples accessing fertility treatment in the public-sector experience and make sense of their treatment. IPA assisted me to do just that.



Before I introduce the reader to the literature reviews (see Chapter 2 and Chapter 3), I provide a bird's-eye-view of the structure of my thesis next to orientate the reader.

Structure of the Study

My study is structured as follows:

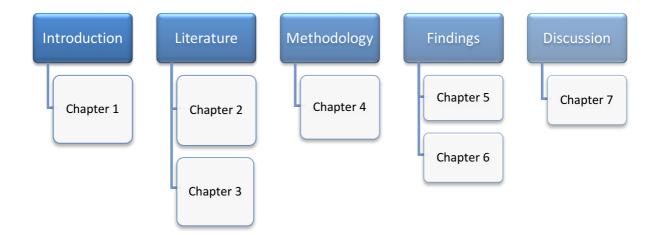


Figure 3: A representation of the structure of this research study.

Chapter 1 provides an introduction to my study by outlining the research problem, followed by the research question and a detailed discussion of the research setting. I discuss the motivation and goals for the project, concluding with the research design and method for the research project.

The second section of the thesis is dedicated to addressing literature on infertility. The literature is comprised of two chapters emulating a bio-psycho-social model (Engel, 1989; White, Williams, & Greenberg, 1996). The first of the two addresses the medical sciences literature, and the other the psycho-social literature whilst acknowledging and incorporating the spiritual literature on the issue of infertility.

Chapter 2 explores the medical sciences literature by providing a broad overview of involuntary childlessness followed by a focused discussion on the childless couple in Sub-Saharan Africa. The causes of non-conception and the assessment and treatment thereof are explored before moving to a focused discussion on the impact of limited economic resources on the provision and accessibility of fertility treatment in the African context.



Chapter 3 explores the psycho-social-spiritual literature, beginning with a discussion on the psychological system. Here I attended to theoretical considerations, research trends, and literature which explored fertility treatment experiences. I conclude the psychological literature review with a critique and identification of a gap in the literature. The sociological system is then addressed, with a discussion on the differences between developed and developing countries' infertility experiences and how this translates into the provision and accessibility of treatment in developing world contexts. I conclude the chapter by addressing the spiritual literature on infertility experiences and explore spirituality and the experience of spirituality as it relates to fertility treatment in different countries and different religions.

Chapter 4 explores the methodology employed in my research project. I begin by discussing my experiences as a researcher, followed by an in-depth discussion on the paradigm and methods of the research project. Quality and ethics are explained in detail before concluding the chapter.

The third section of the thesis is dedicated to the findings, which is segmented into two parts as they related to two master themes that shaped couples' experiences of fertility treatment: (i) Contexts that shaped participants' experiences of fertility treatment, and (ii) Coupleship experiences of fertility treatment and their coping experiences during fertility treatment.

Chapter 5 attends to contexts that shaped couples' experiences of fertility treatment. Private healthcare context experiences are addressed before exploring participants' public health care experiences.

Chapter 6 reports on participants' experiences of coupleship during fertility treatment. Couples' reflections on their experiences of their partner during treatment are explored, followed by an extensive discussion of couples' joint fertility treatment experiences. I conclude the findings with a discussion on the coping experiences of the participants during fertility treatment. Here I report on couples' ability to mobilise during treatment and the support systems that facilitate their ability to cope. I close the chapter with the couple as expertand as imparting insights useful for other couples going through treatment as well as for healthcare professionals in a supportive role for couples going through fertility treatment.



Chapter 7 concludes the thesis by reflecting on the research process, the contribution this study makes to the body of knowledge in psychology and addresses the limitations and recommendations for future research.

Conclusion

In the first chapter, I introduced the reader to my study. In it, I outlined the research problem and the research question, and provided a detailed discussion of the research setting. This was followed by a discussion of the motivating factors and goals for the project. I closed the chapter by briefly describing the research design and method for the research project, and highlighted the structure of the thesis for the reader.

The subsequent chapter is preceded by a preamble to the section, explaining the rationale for why I chose to conduct two literature reviews on the topic of infertility. Come with me now.

PART B





REFLECTIONS

I am fascinated. As a child, I enjoyed consciously walking barefooted on the grass because I wanted to feel the crunch of the grass on my soles, not just hear it. I wanted to know how different things felt before I made up my mind about options that life confronted me with. I wanted to know why my parents had to sneak their one set of friends in to our home and why we had to sneak in to a certain suburb to visit them too. Growing up in Apartheid South Africa as a white immigrant child, I asked many questions and got answers -not always ones that I fully understood - and I remember challenging many things. Perhaps I am defending myself a little, but when I was critical of things, I was asking so that I could understand... so that I could "get it". Admittedly I have relied on my senses a lot; what I see, hear, smell, feel, and taste physically has always informed my attempts at understanding my world.

As I share my thoughts here I am reminded of long drives with my Dad as a young girl. The car became a place of excitement and enquiry about many things. Questions I would ask him, sometimes stimulated by things I would see on the road, or by the conversations we would have, or something I heard on the radio... it would inevitably stir up commentary and wonder. I was around nine years old when, after hearing the radio commentator on the news broadcast "Elton John has announced that he is homosexual", I asked my dad what this word meant. He explained in a way that I could understand the concept. Our conversation jarred many questions. Our entire trip was navigated by a question I put to my dad: "So, do you think when he writes love songs, he is writing them about the man he loves?" I further asked him about the incongruence of Elton John's music videos that had him singing love songs to a woman, when these songs may have expressed the love he felt for a man. I wanted to make sense of experiences; inconsistencies-and-all. Curiosity is part of my identity. Wanting to understand how someone experiences.

I love scuba diving and as I think about my most recent dive, I am vividly reminded of the flood of experience. There is the experience of getting set up, putting your kit on, sitting on the boat, setting up your cylinder, checking your buddy, rinsing your mask and putting it on, and finally, when all kitted up, rolling off the boat into the sea. The feeling of the cold sea water around my entire body, the bubbles around me and then...breathing while submerged in water.



Amazing!! Personally, I prefer deeper dives, where the descent is an experience all on its own. The coexistence between sea life and manmade structures that have had an unfortunate turn, lying on the seabed for me to explore, is a breathtaking experience, to say the least. The immensity of the ocean, juxtaposed by the intricacies of coral and its inhabitants, become a sensory experience that is sometimes difficult to articulate and a challenging task to take it all in. When someone politely asks "So, how was your dive?" it is a tricky question to answer fully. Much like diving, as I immersed myself in the literature, it became a deep dive for me on many levels: academically, personally, professionally, and socially. Submerging myself into the expanse of fertility literature, felt like a multilevel dive, impossible to take it all in and report on the entire breadth of work executed in the field. As I felt lost at times in navigating the depths of the literature I quickly realised I needed something to anchor, and at the same time, guide me.

Randolph's (2009) guide to literature review writing provided me with both a lifeline and a compass to steer me back on track when I felt the quicksand of insurmountable literature grab hold. I found myself drifting back to this article time and time again when I experienced the literature as enormously dispersed. His guidelines refocused me, taking me back to the purpose and goal of what I was trying to investigate and then later communicate. In his paper, he provides a guide that I think is specifically useful for doctoral students, like me, who may work independently for the greater portion of their studies. Randolph (2009) describes a literature review as an opportunity for an author to demonstrate their knowledge of their topic to the academic community. It further serves to inform the author of the influential researchers in the field and can, with some modification, become a publishable document (LeCompte, Klinger, Campbell, & Menke, 2003). The literature review may also provide a platform for integrating new findings to previous findings in the discussion component of the thesis. As I understand it, the literature review may be viewed symbolically as providing the historical story to the topic and the findings of the dissertation continue that story, to perhaps in time, appear in another author's literature review.

Randolph (2009) describes many sophisticated methods to approach the literature review, but I found his concise five step approach relatable and easy to work with. In it, he highlights the parallel between the steps followed in conducting and then communicating the literature review, and the stages followed in conducting the research project. He states that the principles that guide primary research can guide the secondary research (literature review). The



components he isolates are: (a) to have a rationale for conducting the review; (b) the research question guides the research; (c) to outline a detailed plan for collecting the data; (d) to follow a detailed plan for analysing the data; and (e) to outline a detailed plan for presenting the data. Although the five components may seem rather rigid, I used them as coordinates as I navigated the literature. The rationale for the subsequent review was to communicate the multiple voices of infertility treatment experience, forever cognisant that I cannot vocalise the treatment without attending to what led to treatment in the first place: infertility. So, what started out as a utopian, straight-and-narrow "infertility treatment experience literature review", increasingly became a process of academic enlightenment, as I began engaging with the various elements of the infertility Rubik's cube. Another rationale of the literature review was to, at every opportunity, highlight pockets in the literature that call for further study. Moreover, the rationale was to provide a uniquely African experience of infertility in all its voices, acknowledging the silences in the developing world's literature. The research question guided the entire research process prior to initiating the project, during the active phases of the research project, and in the entire process of communicating the research. The plan for collecting the literature and analysing the literature was guided by the rationale for the project and the research question, which I applied to the reading of the literature. This was not always successful, as at times I found myself lost in the wilderness of what I found "interesting", but not always relevant. My thoughts were that creating headings were a good starting point to address the research question, providing me with a checklist of what may be useful to address. The reading became an interactive process, with the headings becoming malleable as ideas developed over time. The synthesis and critical review of the literature continued until the very end, with the research question providing the backdrop to the evaluation of the literary contributions gathered. The last factor Randolph (2009) talks about is a plan for presenting the data. I experienced this as a tall order. The conundrum presented to me as this: How do I communicate the vast landscape of literature that is so obviously multifaceted and far from linear, in a manner that demonstrates this and is in line with the principles of academic prose? The answer is quite simply that, since the moment I engaged with infertility, I recognised the three-dimensionality of infertility and its implications for treatment. Can I, working within the boundaries of the English alphabet, adequately exemplify that here... fully? Probably not. The metaphor of the Rubik's cube came to mind as I found myself descending deeper into the field of infertility experience. It is my hope that this metaphor, if kept in mind throughout, may help to convey the dimensionality of a field of interest that I think is far from ever being fully understood. The Rubik's cube was my plan for communicating the thesis. The cube itself represents infertility experience, with the



vast number of combinations representing a glimpse of the varying facets of experience for couples who experience involuntary childlessness and its treatment.

I dedicated a chapter to the medical science's (biological system) literature, followed by a separate chapter dedicated to health psychology's (psychological system), medical sociology's (social system), and spiritual (spiritual system) contributions to the field of involuntary childlessness. Although I attend to the literature reviews separately, this was merely for containment and "handling" of the information. In so doing, it was my hope that by narrating the information in a compartmentalised fashion, it would avoid the breadth of knowledge becoming a muddy pool of words, and would, therefore, read easier. It was important for contributions addressed in these two literature reviews to speak boldly and concisely in their isolated forms, but at the same time, being mindful that their stories speak to human experience in its fullness: never static. The figure below is an illustration of how one could view the multifaceted nature of infertility and the forthcoming literature reviews, albeit that it does not encompass the ebb and flow between each facet.



Figure 4: Involuntary childlessness as a bio-psycho-social-spiritual experience

To navigate you through the literature, I begin the medical literature review by considering the global infertility research trends and contributions made in the field, much the same as a dive master would orientate the diver by describing the nature of the dive and what one would expect to see at the site. Guided by the research question, the discussion narrows to a focused discussion on the experience of involuntary childlessness in sub-Saharan Africa.



Following the medical literature review, I begin the psycho-social-spiritual chapter by discussing involuntary childlessness from a psychological perspective. Thereafter, I discuss sociological and spiritual literary contributions on infertility experiences. In addition, I outline research contributions which focused on developing and developed countries' experiences of infertility, before concluding each sub-section on fertility treatment experiences in particular.



CHAPTER 2: LITERATURE REVIEW I

Exploring Medical Sciences Literature

Sometimes, I feel the fear of uncertainty stinging clear And I can't help but ask myself how much I'll let the fear take the wheel and steer. It's driven me before, and it seems to have a vague, Haunting mass appeal. But lately I'm beginning to find that I Should be the one behind the wheel.

"Drive"

(Boyd, Einziger, Kautunich, Pasillas Ii, & Kilmore, 2000, track 8).²

² The lyrics of this song resonated with me as I reflected upon how couples who face the uncertainty that comes with infertility, may attempt to gain control of their circumstances by seeking medical advice.



Introduction

What does the biomedical community say about the physical experiences of delayed conception for the person(s) who are experiencing it? Involuntary childlessness is depicted in the literature as a multidimensional health issue, which can significantly impact the individual and couple system, and has the potential to reverberate into multiple contexts (Daly & Bewley, 2013; Saridi & Georgiadi, 2010). One in six couples experiences infertility, which equates to an estimated 60-80 million infertile couples worldwide (Ombelet & Campo, 2007; Salhan, 2011); the largest proportion of which, resides in developing countries, where Africa reportedly has the highest global incidence of infertility (Bambra, 1999). This in itself is problematic, since African countries are generally pronatalistic, with many cultures placing great importance on expanding the family unit (Van der Spuy, 2009). The incidence of voluntary childlessness in Africa is low. Yet, research has shown a high incidence of infertility in Africa (Dyer, Abrahams, Mokoena, Lombard, & Van der Spuy, 2008; Ombelet & Campo, 2007). The impact and resultant implications of this contradiction are far reaching, with cultural, individual, economic and social contexts being affected (Hammarberg & Kirkman, 2013; Ombelet & Campo, 2007).

The provision of healthcare services as a whole in developing countries is diametrically opposite to those offered in developed countries. Couples attempting to access fertility treatment in resource-constrained communities are often faced with a healthcare system that is challenged by financial constraints, limited budgets and infrastructure issues (Robert & Nachtigall, 2006; Sharma, Mittal, & Aggarwal, 2009). This further compound the plight of couples in Africa who experience difficulty in conceiving, as the road to accessing and receiving treatment may not be straight and narrow. Infertility as a public health issue within the developing world context requires urgent multidisciplinary attention. In an attempt to understand the terrain of involuntary childlessness, a review of the biomedical literature is necessary, prior to broadening our understanding of the psychological, social and spiritual literature.

This literature review will focus on surveying the contributions the health sciences have made in understanding infertility, its causes, and treatment modalities. Furthermore, it will address the prevalence of involuntary childlessness in Africa, the impact of economic resources on provision and accessibility of fertility treatment in Africa, as well as the provision of fertility treatment options available in the South African public health context. I turn now to an overview of involuntary childlessness.



Overview of Involuntary Childlessness

An investigation of the medical literature on childlessness led me down varied avenues, each meandering and interconnected, and all leading back to a central plane: a Rubik's Cube highlighting the conundrum of infertility. Each square of the Rubik's represents an intricate facet to be considered in prevention, understanding, assessing, and treating this reproductive puzzle. In order to begin to understand the global picture of this puzzle, it became increasingly apparent to me that if we work in the field of reproductive health, a universally accepted working definition of infertility is important, not only for conducting research, but also in assessment and treatment protocols.

The departure point: "defining infertility", presented a collage of criterion that is employed within the fields involved in reproductive health. The definition of infertility differs within the various contexts and fields it is being examined in. This has implications for how research in to the phenomenon is conducted and what facet will be researched. It has further bearing on the research findings and how they are recorded and reported. Comparative studies can be arduous when attempting to determine the prevalence of infertility between countries (Gurunath, Pandian, Anderson, & Bhattacharya, 2011). This can further compromise the management of infertility in the long run, posing a challenge when attempting to standardise procedures, and when comparing outcomes of procedures in different regions and countries (Charlish & Davies, 2007; Gurunath et al., 2011; Marchbanks, Petersen, & Rubin, 1989; Reis, Xavier, Coelho, & Montenegro, 2013; Zegers-Hochschild et al., 2009). Therefore, consideration of the contributors to the collage of definitions is important, as each has unique insights within their areas of specialisation.

A systematic review of infertility related prevalence studies by Gurunath et al. (2011) showed that a distinction is made between a clinical and demographic definition of infertility. Demographers, for example, define infertility as childlessness in a population of women of reproductive age (15-49 years), who have had unprotected sexual activity for five or more years, are not breastfeeding, and who maintain a desire to have a child (Gurunath et al., 2011). There are disability studies that view infertility as generating disability as it impairs a person's/couple's functioning. Research shows that an estimated 34 million women, mostly from developing countries, are faced with infertility, which is a consequence of maternal sepsis and unsafe abortion practices. Infertility in women has been ranked the fifth highest serious global disability (World Health Organization & World Bank, 2011). Epidemiologists' focus is



on the surveillance of trends, and classify infertility as women of reproductive age (15-49 years) who report trying, unsuccessfully, to fall pregnant for two or more years (Gurunath et al., 2011; World Health Organization, 2015). In a move to obtain a uniformed, generally accepted, clinical working definition, the World Health Organization (WHO) and the International Committee for Monitoring Assisted Reproductive Technology (ICMART) define infertility as a disease of the reproductive system, denoted by "the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse" (Zegers-Hochschild et al., 2009, p. 2686). This definition gives clear parameters on what is medically considered "infertility", which in turn guides medical research and treatment protocols. The WHO has acknowledged the seriousness of involuntary childlessness, declaring it a public health issue (Sharma, et al., 2009).

The clinical understanding of infertility can be categorised in to two main groups: primary or secondary infertility. Primary infertility can be seen as the absence of a live birth for women who desire a child and have been in a union for at least five years, during which time they have not used contraceptives (Mascarenhas, Flaxman, Boerman, Vanderpoel, & Stevens, 2012). A published report by the WHO further adds that women whose pregnancy miscarries or whose pregnancy results in a stillborn child, without ever having had a live birth, would be considered presenting with primary infertility (WHO, 2015). Secondary infertility can be seen as the absence of a live birth for women who would like to have a child and have been actively trying to conceive for five years since their last child, during which time, no contraceptives were used. The difference in the two categories is whether or not the couple has ever had a pregnancy which has led to a live birth (Mascarenhas, et al., 2012). The clinical understanding of infertility, which seems to have a specific focus on the female, can be seen in the research contributions of the Health Sciences.

When examining the Health Sciences contributions, it is clear that the subject of the research is usually the female(Charlish & Davies, 2007; Demouzon & Logerotlebrun, 1992; Dyer et al., 2005; Sultana, Rahman, & Nagaraj, 2011).In the field of women's reproductive health in particular, infertility treatment research is dedicated to the causes of infertility cited in the female reproductive system, and interventions that are utilised are either curative or serve as symptomatic treatment in order to attempt to achieve successful conception (Demouzon & Logerotlebrun, 1992; Sultana et al., 2011). The field of reproductive biology in particular, makes research contributions in the areas of both female and male reproductive difficulties.



However, the literature seems to display a pervasive focus on the female patient when researching the aetiology, assessment and treatment of infertility in general (Schenker, 1997; Sultana et al., 2011), and to a lesser degree, the male as the focal point of patient research (Daly & Bewley, 2013; Esteves, Miyaoka, & Agarwal, 2011; Mohsen, Smith, & Ping-Chi, 2011; Morakinyo, Iranloye, Daramola, & Adegoke, 2011). One common thread in all the research reviewed here, is the quest for an enhanced understanding of impaired fecundity.

What is evident in the literature is the juxtaposition in Africa between valuing fertility on the one hand, versus the high non-conception rates in Africa, on the other. A discussion on the prevalence rates in sub-Saharan Africa follows.

The Childless Couple in Sub-Saharan Africa

Reproductive health can be described as a state of physical, mental and social wellbeing, pertaining to all matters regarding the reproductive system. It not only includes the absence of disease, but encompasses the individual's right to reproduce, and includes free will to decide when and how often to reproduce. Conversely, infertility continues to be experienced as a global problem affecting between 60-80 million men and women, with the vast majority residing in resource-poor countries (Sharma et al., 2009). In 2002, an estimated 186 million ever-married women of reproductive age (15 - 49 years) presented with either primary or secondary infertility (Rutstein &Shah, 2004). Recent surveys demonstrated that the global prevalence of infertility can be quantified at approximately 9% (Hammarberg & Kirkman, 2013).

Demographic studies demonstrate declining fertility rates across all continents, however, the decline is not equal everywhere, with significant differences being noted between continents in some cases (Van Bavel, 2013). In high-income countries, approximately 15% of the population is faced with infertility, with a greater percentage being seen in resource-poor countries, ranging from 9%-30% (Petraglia, Serour, & Chapron, 2013). Higher infertility prevalence rates in resource-constrained countries, as compared to that of developed countries, demands global attention. Ascertaining the precise pervasiveness of involuntary childlessness is challenging since it requires accurate prevalence calculations, which rests on the accuracy of diagnosis protocols and pre-registration of procedures. These can be either absent or unreliable in some developing countries (Ombelet & Campo, 2007; Sharma et al., 2009). Analysis of data in poor countries can be flawed as it is reliant on advanced healthcare systems and infertility



studies often extrapolate fertility data to make inferences on infertility rates, which can underestimate the prevalence (Sharma et al., 2009). Therefore, the reliability and validity of data collected regarding the incidence of infertility in sub-Saharan Africa may not adequately portray the pervasiveness of this health issue.

In sub-Saharan Africa, up to one third of couples are said to be infertile, with prevalence rates differing from region to region. Prevalence rates as high as 30-40% has been reported in some parts of sub-Saharan Africa (Leke, Oduma, Bassol-Mayagoitia, Bacha & Grigor, 1993). The national average for prevalence ranged between 12.5 to 16% (Sharma et al., 2009). In Gambia, 9% of couples struggle with non-conception. In comparison, in north-western Ethiopia it is estimated that 21.2% of couples confront the reality of infertility. These in comparison to Nigeria, where prevalence rates lie between 20 and 35%, which is cited as the most common reason for gynaecological consultation in Nigeria (Hammarberg & Kirkman, 2013; Okonofua,1996; Ombelet & Campo, 2007). Southern African countries, such as Botswana, Zimbabwe, and Lesotho report a prevalence of between 15-22%, which is much higher than rates of 8-13% found in most other Eastern African countries (Sharma et al., 2009). What does this compelling evidence mean for those couples who come from pronatalistic communities?

The degree to which involuntary childlessness affects couples in resource-poor countries can be further understood by gaining insights in to primary and secondary infertility prevalence rates. Primary infertility affects approximately 3% of women in Africa, with much higher secondary infertility rates of 23% being seen in the Central African Republic (Larsen, 2009. The disparity between primary and secondary infertility prevalence rates in sub-Saharan Africa can be attributed to the transmittal of preventable diseases, such as Sexually Transmitted Infections (STIs) and Human Immunodeficiency Virus/ Acquired Immunodeficiency Syndrome (HIV/AIDS). Tuberculosis and STIs such as Chlamydia, Gonorrhoea and HIV/AIDS are considered as the leading causes of preventable secondary infertility in sub-Saharan Africa. This demonstrates that comprehensive healthcare systems need to be made available to people in resource-poor countries, which face the plight of infertility. These healthcare facilities should focus on providing preventative treatment and education to patients, as well as the provision of evaluation and treatment focused services that are affordable and accessible. This is a tall order in many sub-Saharan countries who face impoverished conditions (Ndowa, Lusti-Narasimhan, & Unemo, 2012; Van der Spuy, 2009).



In exploring involuntary childlessness further, I now turn to medical sciences research that has centered on investigating the aetiology of non-conception.

Causes of Non-Conception

In tackling the Rubik's cube and exploring further how it can be understood in different fields that work within reproductive health, these meanderings have led to exploration of another side to the cube: delving in to the possible causes of infertility. Research contributions from the Health Sciences by-and-large examine the organic causes of infertility, demonstrating that infertility can be largely attributed to endocrinological, genetic, anatomical, and immunological factors (Agboghoroma & Giwa-Osagie, 2012; Ombelet & Campo, 2007). Adjunct to the causes of infertility, identification and consideration of the source of the infertility is important as it has treatment implications.

The source of infertility can stem from either the female or male partner, and in some cases, can involve both partners (Dunson, Baird, & Colombo, 2004; Hammarberg & Kirkman, 2013; Salhan, 2011; Sharma et al., 2009). It is estimated that one-third of couple infertility is due to male factors, another one-third to female factors, and the other one-third can be attributed to couple factors or has no known cause (Hammarberg & Kirkman, 2013). An expert group commissioned by the National Health Service (NHS) in the United Kingdom (UK) for the investigation of infertility provision in 2009 (Department of Health, 2009), cited factors that can cause both male and female infertility as ranging from: genetic factors; general health factors such as diabetes mellitus; thyroid disorders and adrenal disease; as well as hypothalamic-pituitary factors. Furthermore, it was found that fertility in both sexes is reduced by smoking, excessive alcohol consumption, and obesity. These lifestyle factors can also influence the efficacy of infertility treatment (Department of Health, 2009). The multiple causes of infertility will be examined in more detail throughout the literature review.

In general, female factors contributing to infertility can vary from ovarian, endocrine, tubal, immunological, endometrial, vaginal and cervical problems (Salhan, 2011; Sharma et al., 2009). In addition, the age of the female partner may play a role in infertility, where female fertility is said to be at its peak during her twenties and significantly declines after the age of thirty (Dunson, et al., 2004; Petraglia, Serour, & Chapron, 2013; Rosenthal, 2002). Male factors affecting fertility can range from immunological, defective spermatogenesis, obstruction of the efferent duct system (Salhan, 2011), and age (Dunson, et al., 2004; Petraglia, Serour, &



Chapron, 2013). Sharma et al. (2009) neatly encase the causes of infertility in to two main groupings. The first group addresses the anatomical, genetic, hormonal, and immunological causes. The second addresses the preventable causes of infertility. The former group can be referred to as the core cause of infertility and is responsible for approximately 5% of the global prevalence of infertility. These causes include, but are not limited to, endocrine and ovulatory dysfunction, presenting in the form of Polycystic Ovary Syndrome (PCOS), hypothalamic dysfunctions and premature ovarian failure (Agboghoroma & Giwa-Osagie, 2012). The latter group is largely caused by infection or iatrogenic causes (from medical treatment received). The type and form of infection can differ between countries as their social, environmental and healthcare systems differ. In Africa 85% of women were given a diagnosis of infertility caused by preventable infection, and 15% caused from medical procedures; this in contrast to 5% in Western Europe that were attributed to iatrogenic causes. According to Sharma et al. (2009), most preventable infertility in couples is a result of one of four factors: reproductive tract infections, healthcare practices, environmental factors, and socio-cultural factors. Considering that most infertility in Africa is a result of preventable causes, I chose to take a closer look at these factors, as they have bearing on infertility experiences in the South African context.

Reproductive Tract Infections

History tells a long story of the existence of STIs around the world. For example, the first well documented Syphilis epidemic occurred in Europe in 1493. During this epidemic, it was not known how the disease was transmitted. Socially, it was believed that women afflicted with the disease, for example, were sinners and criminals (Swinton, Garnett, Brunham, & Anderson, 1992). Whilst communities still hold strong social beliefs regarding STIs today, we have come a long way in our biological understanding of STIs, not only in ascertaining how the infections are transmitted, but also the impact the infections have on general and reproductive health.

STIs are a major cause of mortality worldwide, with Gonorrhoea remaining a major global health problem. Lack of treatment can result in pelvic inflammatory disease in women, leading to infertility or ectopic pregnancy. Up to 10% of women who remain untreated for Gonorrhoea and Chlamydia infections may become infertile. Urogenital Gonorrhoea is asymptomatic in 50% of women, leaving the infection undiagnosed and untreated in many cases, leaving many women with severe reproductive complications (Agboghoroma & Giwa-Osagie, 2012; Ndowa, Lusti-Narasimhan, & Unemo, 2012).



In sub-Saharan Africa, reproductive tract infections caused by STIs, account for more than 70% of pelvic infections, most of which are attributed to Chlamydia, which can cause fertility issues in both men and women, and Neisseria Gonorrhoea can cause infection of the fallopian tubes, which requires immediate treatment (Ndowa, Lusti-Narasimhan, & Unemo, 2012; Sharma et al., 2009). Resource constrained countries are challenged by the strain STIs can place on the health care system, which in turn further compounds the capacity for some couples to access and receive treatment to assist them in their endeavours to have children (Agboghoroma & Giwa-Osagie, 2012; Van der Spuy, 2009). Thus, I will focus specifically on this area of research as it contextualises this research project in particular.

Of all the STIs, HIV has had a colossal impact on fertility in Africa. Having a diagnosis of HIV/AIDS can conflict with couples' reproductive aspirations, where they are often faced with "safe sex" advice from medical personnel. With little attention being given to the couples' wish to have children, despite their HIV/AIDS status, where does this leave these couples? This can have a profound impact on couples in Africa, where fertility is highly valued (Van der Spuy, 2009). "Childlessness" in Africa encompasses divergent elements, such as: infertility, foetal and neonatal deaths, and young children who die at the hands of the HIV/AIDS virus. Furthermore, many women in Africa have no knowledge of their HIV status when attempting to achieve pregnancy, and fertility decisions are made independent of their status. HIV/AIDS has had little impact on sexual behaviour, where the need to reproduce and the social stigma that comes with childlessness, have been powerful social forces in decision making (Van der Spuy, 2009). Furthermore, other STIs, such as gonorrhoea, significantly enhance the transmission of HIV (Ndowa, Lusti-Narasimhan, & Unemo, 2012). In resource-poor countries, HIV/AIDS can present a mammoth obstacle to a couple's desire to reproduce.

The tentacles of HIV/AIDS can extend deep in to the couple relationship, where in some instances, the loss of a partner, reduced frequency in sexual intercourse, and illness further compounds conception difficulties. In women, HIV/AIDS and other STI's can co-create tubal damage, menstrual disorders and in later stages of the illness it may reduce ovarian response to ovulation induction. In men, HIV/AIDS can alter spermatogenesis (Van der Spuy, 2009). In Africa, this picture is a gloomy one, where state provided infertility treatment for HIV positive couples, is largely denied. With an African healthcare system that is under tremendous stress in general, the HIV positive couple proves to be an even more specialised area, needing expert care, which is often unavailable in resource-poor areas. Therefore, the impact of HIV/AIDS on



reproductive health needs attention, with resources being developed to address, amongst others, the infertility management component of the illness (Van der Spuy, 2009). Africa is not alone in its plight, where other developing countries face preventable infections which negatively impact fertility.

The Indian subcontinent provides another example of resource poverty, which faces its own battle: Tuberculosis (Sharma et al., 2009). Genital tuberculosis appears to be a common cause of both male and female infertility in India, and presents as a major factor in both primary and secondary infertility. Genital tuberculosis is cited as a cause of Asherman's syndrome, which causes oligomenorrhoea (light, or infrequent menstruation) or amenorrhoea (absence of menstruation) with resultant infertility. Female genital tuberculosis is common in developing countries such as India, with the fallopian tubes and endometrium being the most affected by the disease (Mondal, 2013; Sharma et al., 2009). In 68% of Indian women presenting with infertility, there was a history of tuberculosis, and 49% of women presenting with tubal factor infertility and had a history of genital tuberculosis. Female genital tuberculosis is both preventable and treatable yet it is one of the leading causes of primary and secondary infertility in India (Sharma et al., 2009). In examining the literature on preventable infections as a cause of infertility, the golden thread seems to be the resource constraints experienced in those areas of the world, preventing adequate medical treatment. Treatment of infection seems to be one of the salient issues to be addressed in resource constrained countries in attempting to prevent infertility.

Treatment of preventable diseases can place strain on an already resource constrained health care system, but it is not the only preventable source of infertility (Serour, 2008). Clinician induced (iatrogenic) damage to reproductive structures is another preventable cause of infertility, which has significant relevance to the African context. Further examination of these healthcare practices follows.

Health Practices

One of the largest female public health issues experienced more so in poorer communities, is the healthcare practice of unsafe abortions (Grimes et al., 2006; Hammarberg & Kirkman, 2013; Ombelet & Campo, 2007; Shah & Ahman, 2009). This warrant particular attention in the literature review, especially as the highest proportion of women experiencing infertility as a result of unsafe abortion practices is in sub-Saharan Africa. One in four women



who have had unsafe abortions, are likely to experience severe complications and seek medical assistance. How is it that this is the picture, when medically induced abortion is said to be one of the safest procedures in modern medicine? The availability of manual vacuum aspiration and non-surgical abortion can reduce abortion-related complications, yet we are faced with 5 million women who seek medical intervention due to complications subsequent to abortion procedures (Shah & Ahman, 2009).

Unsafe abortions are preventable causes of maternal death and illness. Yet, it accounts for an estimated 13% of global maternal deaths. In sub-Saharan Africa, the burden per 1000 unsafe abortions is more than six times as high and four times as high in Asia, when compared to developed countries. Unsafe abortions have been the leading cause of 70 500 maternal deaths worldwide, almost all of them occurring in developing countries. Over half of these deaths were in Africa and 34% in other resource constrained countries (Shah & Ahman, 2009).

Additional consequences of unsafe abortions are numerous: sepsis, haemorrhage and trauma, upper genital tract infections, loss of productivity, economic burden on public health systems, stigma and long-term health issues, such as infertility, are some of the inadvertent consequences of unsafe abortion (Grimes et al., 2006; Hammarberg & Kirkman, 2013; Ombelet & Campo, 2007; Shah & Ahman, 2009). Of the 5 million women who experience disability each year because of unsafe abortion, more than three million are likely to endure the effects of reproductive tract infections, and 1.7 million are estimated to develop secondary infertility, with 24 million women estimated to be currently experiencing secondary infertility directly related to unsafe abortion practices (Shah & Ahman, 2009). This is a bleak picture of health care practices which have unintended consequences.

Health care practices in resource-poor countries can create, rather than prevent or cure, medical conditions. Practices such as: Unhygienic obstetric procedures, outdated treatment methods, cauterisation of the cervix, lack of trained medical professionals, provision of subminimum standard healthcare, unavailability of medication, and traditional therapies where chemicals and herbs are inserted in to the vagina, have all been cited as causes of infertility in low resource contexts (Hammarberg & Kirkman, 2013; Ombelet & Campo, 2007; Sharma et al., 2009). The question simply is this: How do we adequately address the multitude of health care needs of people in resource impoverished communities?



There are numerous debates on how to move forward. It is apparent though, that there is a dire need for community education on reproductive health. Furthermore, continuous professional development of medical personnel is imperative, so that we lower the incidence of preventable causes of infertility due to healthcare practices. The provision, affordability and accessibility of healthcare services and expertise are warranted, so that community members can utilise resources to make informed reproductive health decisions. Reproductive health is also intricately connected to both internal and external environmental factors, which is explored in the subsequent section.

Environmental Factors

Amongst the list of preventable factors that have been flagged as possibly contributing to infertility in both partners, are those that fall under the umbrella term of environmental causes. When considering environmental factors, a distinction can be made between the external environments (the environments individuals are in contact with and the physiological impact this contact can have on the individual), and internal environment (constituting the physiological system of the individual and the impact of the internal environment on fertility). Lifestyle factors, where an individual is in contact with an environmental element, or introduces a foreign element in to their internal environment, can potentially have a negative impact on conception, depending on the environmental factor. Lifestyle factors can affect reproductive health, and careful examination of some of these factors illustrates the impact of exposure on the individual (Demouzon & Logerotlebrun, 1992; Negro-Vilar, 1993; Rosenthal, 2002; Sultana, et al., 2011).

According to Daly and Bewley (2013), the population trying to start a family is ageing and with that, gynaecological and obstetric complications are increasing. Delayed child bearing (the choice to have children later in life), can significantly impact fecundity (Daly & Bewley, 2013; Petraglia, Serour, & Chapron, 2013). Assisted Reproductive Technology (ART) is available, but treatment may sometimes be unhelpful when up against the ageing process (Daly & Bewley, 2013). The steady decrease in fertility with maternal age can be associated with an increase in spontaneous abortions and foetal genetic abnormalities. The latter is likely due to a steady decrease in number and quality of oocytes (the immature female reproductive cell prior to fertilisation) (Daly & Bewley, 2013; Hassan & Killick, 2003; Petraglia, Serour, & Chapron, 2013). The increasing age at which men and women choose to procreate is correlated with the increasingly longer time it takes to conceive. Hassan and Killick (2003) found that women who



were 35 years old or older, were 2.2 times more likely to take more than two years to conceive, than women who were 25 years old. They cited age as the contributing factor, and adjusted for factors such: as frequency of sexual activity, Body Mass Index (BMI) (which is calculated as weight in kilograms divided by the square height of the individual in meters), smoking and other lifestyle factors (Petraglia, Serour, & Chapron, 2013). The same could be said for men older than 45 years of age, where increasing male age had a negative impact on male fertility, impacting semen volume (Dunson, et al., 2004; Li, Lin, Li, & Cao, 2011). The aging man is at greater risk for testicular trauma, genital inflammation, cancer, hormonal changes, systemic diseases, and conditions which may require surgery, all of which can impact male fertility (Petraglia, Serour, & Chapron, 2013). A magnified look at the consequences of the impact smoking and caffeine use has on fertility, as well as the implications diet, weight and exercise have on the fertility profile of men and women follows.

Additional lifestyle factors, such as smoking, can compromise both male and female fertility. Men who smoke run the risk of decreased sperm production, motility and changes to morphology, with an increased risk of sperm DNA (Deoxyribonucleic Acid) damage. In women smokers, the follicular microenvironment and hormone levels in the luteal phase of her cycle may be altered. Nicotine changes fallopian tube contractility, impairing oocyte transport and sperm-egg interaction. Cotinine (a metabolite of nicotine) and cadmium have been detected in follicular fluid of female smokers and in females who do not smoke, but their partners do. These have adverse effects on the developing follicle. Smoking also affects the fallopian tubes, which increases the likelihood of ectopic pregnancies and secondary infertility. Studies have shown that conception is significantly delayed in those exposed to cigarette smoke (Petraglia, Serour, & Chapron, 2013). Smoking is not the only environmental factor that negatively impacts fertility.

Prolonged exposure to other toxins such as glues, solvents, pesticides and chemicals are believed to impact negatively on fertility. Environmental toxins have been said to contribute to affecting sperm count and may play a role in oestrogen related conditions in females ranging from endometriosis to fibroids (Demouzon & Logerotlebrun, 1992; Petraglia, Serour & Chapron, 2013; Rosenthal, 2002; Sultana, et al., 2011). Sharma et al. (2009) cite alcohol, tobacco and caffeine consumption as having a negative impact on fertility (which I discuss in more detail shortly). Furthermore, they cite dietary deficiencies of iodine and selenium, and



exposure to aflatoxin, as impacting fertility. Moreover, it was found that fertility in both sexes is reduced by obesity (Department of Health, 2009).

Weight, diet and exercise, can negatively impact fertility in both men and women. Obesity and low body weight affect the female reproductive functioning by creating hormone imbalances and ovulatory dysfunction. Furthermore, high BMI in women has been associated with adverse pregnancy disorders such as gestational diabetes and hypertension. Lifestyle modification programs that encourage exercise, weight loss and good eating habits, have demonstrated an improvement in women's reproductive function, by facilitating spontaneous ovulation. In men, a BMI less than 20, or more than 25, has been associated with reduced sperm quality. Thus, to improve female and male reproductive ability, having a healthy and varied diet and moderate exercise is encouraged (Petraglia, Serour, & Chapron, 2013). Healthy living, which attempts to eliminate substances that can alter hormonal levels, is usually advised. This may include substances such as caffeine and alcohol.

Caffeine and alcohol consumption have also been associated with reduced fertility. Caffeine has been cited as altering female hormone levels causing ovulation, producing higher levels of early follicular oestradiol, and there is strong evidence supporting that high levels of caffeine consumption are linked to reduced chance of pregnancy. Alcohol can impair conception by creating an alcohol induced rise in oestrogen levels, which reduces Follicle-stimulating Hormone (FSH) secretion, which further suppresses folliculo-genesis. It may also impact ovulation, blastocyst development, and implantation. In men, chronic abuse of alcohol has been reported to reduce libido, and impacts negatively on both hormone levels, and sperm production (Petraglia, Serour, & Chapron, 2013). Stress is another environmental factor which has received attention by workers in reproductive health care.

Stress is experienced as mental or emotional strain which results from adverse or demanding circumstances. Stress can have a profound effect on the reproductive system. In men, stress can lead to a decrease in sperm count, motility and morphology, and in women stress can lead to anovulation and amenorrhea. Stress has also been cited in affecting endocrine and other regulatory systems. Immunity and the autonomic nervous system can be affected, which can impact reproductive health. Sejbaek, Hageman, Pinborg, Hougaard and Schmidt (2013) found that women struggling with severe and recurrent depression sought fertility treatment and some women who did seek treatment were less likely to disclose depressive



symptoms before or during fertility treatment. Furthermore, the experience of stress can lead to changes in eating, nutrition, and exercise behaviours, which can further compound the fertility picture (Negro-Vilar, 1993; Petraglia, Serour, & Chapron, 2013).

"Lifestyle factors" seems to be an area where reproductive health workers are able to give the most guidance and support to patients. Referral to other healthcare professionals can be made where necessary, and/or recommendations on the benefits that living a healthier lifestyle can have on fertility, can be worked through concretely with those struggling with conception. However, socio-cultural factors may not be as easy to manage within the reproductive health sector, as some form part of cultural practices, and others broach social and cultural dogma, which can represent precarious discussions. This is examined further in the discussion that follows.

Socio-cultural Factors

Each community is regulated by norms and customs that are socially embraced and practiced. Norms and values influence attitudes and behaviours of people living in communities, where traditional and cultural practices are noticeable demonstrations of beliefs in practice. Some cultural practices can be positive, whilst others can be harmful, affecting the general health and wellbeing of certain individuals. Harmful traditional practices continue and become deeply embedded in certain societies. Many reasons have been put forward as to why harmful traditional practices continue: poverty; poor access to education; and due to the continued reverence of a patriarchal system. Women and girl-children are at particular risk for harmful traditional practices, which in some cases violate the integrity of women and female children, such as in the case of Female Genital Mutilation (FGM) (Moges, 2003).

Societies that are pronatalistic, may advocate for women undergoing various treatments which are not medically proven and which may result in damage to their reproductive system. Socio-cultural practices such as FGM, which is performed in certain parts of Africa and the Middle East, continues as it is a condition for marriage in some communities, where some men will not marry an uncircumcised woman as they fear breaking social norms. In some communities, men pay the parents of a bride, which is dependent on the woman fulfilling traditional norms, where FGM may be one such norm. FGM may also be a religious requirement and may also symbolise the commitment of a community to continuing tradition (Moges, 2003). FGM is often performed by local midwives who have limited knowledge of



anatomy. Haemorrhage, sepsis, obstructed labour, and infertility are some of the consequences of this practice (Hammarberg & Kirkman, 2013; Sharma et al., 2009). In resource-poor communities, where availability of and access to healthcare facilities can be challenging, this can negatively impact fecundity.

An assumption often made is that infertility does not present as a "problem" in resourceconstrained communities, where fertility rates are high. This assumption is challenged by research which demonstrates that the reality and consequence for women, who experience involuntary childlessness in low-income countries, can be dire. In Africa, women are frequently stigmatised, ostracised, isolated and neglected by their family and their community for failure to achieve pregnancy (Hammarberg & Kirkman, 2013). The irony is that in some cases, certain socio-cultural practices may be directly linked as a casual factor for a woman experiencing infertility. In Africa, women may be inclined to consult traditional healers, in an attempt to understand the aetiology of their childlessness, and to receive treatment. A study undertaken by Dyer, Abrahams, Hoffman and Van der Spuy (2002), found that women who consulted traditional healers, received "herbs" or "medicine" to drink in order to be "cleaned". Some women were told that their infertility was due to a bewitchment by a jealous woman, while others were considered possessed by ancestors. Others believed that witchcraft prevented doctors from identifying the cause of their childlessness. In my opinion, comprehensive reproductive education is indicated whilst being mindful and respectful of cultural belief systems.

Low literacy rates, a consequence of poor education in Africa, have been cited as creating barriers to women accessing information regarding reproductive health and disease. Information is imperative as it is the basis for prevention and treatment. Healthcare workers also need to be acutely aware of the context in which they operate. Careful consideration should be paid to the personal experiences of their patients in light of cultural views held in the community regarding childlessness. Furthermore, healthcare workers should be mindful of the level of education of their patients, so that information delivery is given in a manner that is understood by the patient, so that clinic attendance is not deterred (Dryer, Abrahams, Hoffman, & Van der Spuy, 2002; Ndowa, Lusti-Narasimhan, &Unemo, 2012; Van der Spuy, 2009). At a larger level, there is a move in the field of reproductive health, to prevent infection, especially in low-resource communities. There is further evidence for lobbying for healthcare facilities that are both accessible and affordable. This calls for governments to treat infertility and its



prevention, with the importance it deserves (Hammarberg & Kirkman, 2013; Ombelet & Campo, 2007; Sharma et al., 2009; Van der Spuy, 2009).

I turn to the evaluation and treatment of infertility in general by examining the development of assessment protocols and treatment modalities over the years to present day. This will lead to a focused discussion of treatment options available to the South African public in both the private and public sectors.

Assessment and Treatment of Delayed Conception

Although delayed conception is common, the process of trying to get pregnant without success can create dissonance on personal, societal, and spiritual levels. It can lead to social and psychological suffering, which can place significant pressure on a couple's relationship (Charlish, & Davies, 2007; Fathalla, 2001). The majority of couples confronted with infertility are faced with inadequate general healthcare facilities where reproductive health treatment is synonymous with the prevention of pregnancy, and with little attention being paid to infertility diagnosis and treatment (Dyer et al., 2008; Ombelet& Campo, 2007; Ombelet, Cooke, Dyer, Serour, & Devroey, 2008). This denotes a great irony in Africa, where on the one hand growing the family unit is prized, yet, on the other hand, infertility and its treatment is a taboo subject in many African cultures, treated with scorn and prejudice. In many instances, childlessness can lead to social isolation and prejudice, domestic violence and neglect, and has great financial impact, to name but a few sequelae (Ombelet & Campo, 2007). Involuntary childlessness is largely overlooked as a public health issue in Africa and has implications for assessment and treatment.

It is important to be cognisant of the vast economic disparities between developing and developed countries (Robert & Nachtigall, 2006; Sharma, 2009). These differences equate to variations in a country's ability to provide infertility treatment infrastructure; the provision of affordable treatment options; and reproductive education programs available to the general population(Daar & Merali, 2002; Luna, 2002; Tangwa, 2002).Fortunately, the WHO has drawn attention to encouraging continued developments of affordable ART in developing countries, with parallel attention given to social and ethical implications in developing countries (Daar & Merali, 2002; Luna, 2002; Tangwa, 2007; Tangwa, 2002).



International evidence-based guidelines for infertility treatment need to be the backdrop to simple, low-cost, and effective treatment options in resource-poor countries (Sharma et al., 2009). Over the span of 30 years, we have seen considerable developments in fertility treatment and ART. A short synopsis of current assessment and treatment practices in follows. This summary serves as an introduction to fertility treatment and does not encompass a detailed discussion of what proves to be a very specialised and broad area of medicine. My intention in the following section is to provide the reader with a rudimentary understanding of fertility management by outlining the assessment and treatment of infertility within the medical context.

First Line Medical Management

Infertility can be managed in divergent ways, in different contexts, depending on the aetiology and the supportive measures indicated. Treatment can range from counselling, lifestyle advice, spiritual guidance, consulting a General Practitioner (GP), gynaecological investigation, medication, surgery, and with ART (Andersen & Erb, 2006; Crawshaw & Sloper, 2010; Fathalla, 2001; Lamar & De Cherney, 2009; Schenker, 1992; Teede, Deeks, & Moran, 2010; Zegers-Hochschild et al., 2009). The course and direction of fertility intervention can be as unique as the couple's unique fertility picture. However, I give a brief synopsis below of the various steps that can be followed when a couple encounters conception difficulties.

First-line medical management is usually orientated around lifestyle counselling to increase the likelihood of conception occurring naturally. Lifestyle counselling may be provided by healthcare providers such as nurses, dieticians, counsellors, social workers, psychologists, or doctors, and will address issues such as weight, lifestyle choices such as addressing smoking and alcohol consumption, caffeine intake, diet, exercise, and management of stress levels (Negro-Vilar, 1993; Petraglia, Serour, & Chapron, 2013). A consultation with a GP may be indicated if the couple has had regular, unprotect sexual intercourse for a year or longer without conceiving. The GP may discuss frequency and timing of intercourse and will assess the general health of each partner. He or she may run preliminary blood tests to rule out any obvious causes for non-conception difficulties. If the tests and preliminary examination provide little to no insight, then a referral to a gynaecologist may be made.

It is recommended that both partners attend each consultation, as the fertility issue may lie with either or both of the partners. Semen analysis and assessment of the menstrual and ovulatory cycle is initiated with the gynaecologist. Lifestyle factors are further explored and



discussed with the couple. If the aforementioned is found to be normal, or a problem is detected, it will depend on the nature of the problem as to whether the gynaecologist can treat it with the view of assisting the couple to conceive, or whether a referral to a reproductive specialist is required. The tests may uncover a problem that is easily treatable; if not, a referral to a fertility specialist is made.

Routine Fertility Treatment

Depending on the financial position of the couple, a decision will be made about whether a referral is made to a private clinic or a public health facility. Prior to initiating fertility treatment, a specialist working in either of the two sectors will discuss and explore each partner's general health and lifestyle. General health advice may be required and carried out before or during treatment (Crawshaw & Sloper, 2010; Demouzon & Logerotlebrun, 1992; Lamar & De Cherney, 2009; Sultana, Rahman, & Nagaraj, 2011; Teede, Deeks, & Moran, 2010).

The specialist's enquiry will endeavour to explore whether the female is ovulating, the man is producing healthy and sufficient quantity sperm, and that the sperm and egg are able to meet. If the specialist suspects that the female is not ovulating, blood tests may be ordered during her menstrual cycle and her ovaries may also be scanned using an ultrasound to assess when and if ovulation took place. For ovulatory problems, hormonal treatment is usually indicated to stimulate ovulation. The man will be asked to provide two or more semen samples for analysis. Under microscopic analysis, the quantity and health of the sperm are assessed. If the sperm count is low, testosterone levels may be checked, and hormonal treatment may be initiated if tests show a testosterone deficiency (Crawshaw & Sloper, 2010; Demouzon & Logerotlebrun, 1992; Lamar & De Cherney, 2009; Sultana, Rahman, & Nagaraj, 2011; Teede, Deeks, & Moran, 2010).

If investigations show that a woman is ovulating and the male partner's sperm analysis is within normal limits, the specialist may investigate further as to why the sperm and egg are not meeting. The specialist may request a post-coital sample, which is a sample of cervical mucus collected after the couple has had intercourse, to test for any obvious incompatibility. The female partner's reproductive system may be examined by laparoscopy to detect any tubal damage or blockages, and to examine all other reproductive organs for any signs of disease.



In many cases, the problem is easily identifiable and treatable. Fertility treatment may include:

- Fertility medication to stimulate ovulation.
- Hormone treatment to encourage sperm production.
- Drug treatment with corticosteroids to suppress the production of antibodies to the man's sperm.
- Microsurgery: for example, to repair damage to the fallopian tubes or male reproductive tubes.
- Other surgery: for example, to remove fibroids (Crawshaw & Sloper, 2010; Demouzon & Logerotlebrun, 1992; Lamar & De Cherney, 2009; Sultana, Rahman, & Nagaraj, 2011; Teede, Deeks, & Moran, 2010).

Following investigations and where other forms of treatment have been considered and/or tried, the treating specialist may advise the couple to consider ART.

Assisted Reproductive Treatment (ART)

When a specialist believes that a couple is unlikely to achieve a pregnancy naturally, assisted fertility treatment is often recommended. The course of treatment will depend on the nature of the problem (Crawshaw & Sloper, 2010; Demouzon & Logerotlebrun, 1992; Lamar & De Cherney, 2009; Sultana, Rahman, & Nagaraj, 2011; Teede, Deeks, & Moran, 2010).

Insemination: Artificial Insemination (AI) and Intrauterine Insemination (IUI).

Insemination procedures are performed in fertility clinics, where a thin catheter, containing the male partner's sperm, is used to put the sperm into the female partner's reproductive tract. There are two insemination methods that can be utilised: One is an AI method, where the male partner's sperm is insertered into the female partner's cervical channel, and the second is an IUI method where sperm is inserted directly into the female partner's uterus. No anaesthetic is necessary as the procedures quick and pose no discomfort to the patient. In some cases, the semen may be treated prior to the procedure in order to remove poor quality sperm (Crawshaw & Sloper, 2010; Demouzon & Logerotlebrun, 1992; Lamar & De Cherney, 2009).

These suitable treatment options for couples who experience difficulties such as impotence, premature ejaculation, a low sperm count, or blockages in the male reproductive



organs and in cases where the female partner's body produces antibodies to her partner's sperm. These methods may also be suggested in cases of unexplained infertility (Crawshaw & Sloper, 2010; Demouzon & Logerotlebrun, 1992; Lamar & De Cherney, 2009).

Donor Insemination (DI). In this procedure, the sperm of men who have donated their sperm to sperm banks is treated and stored for later use. Donor sperm may be used instead of the male partner's sperm in cases of impotence, defective sperm, azoospermia, and in cases where singlewomen or same-sex couples wish to have children (Crawshaw & Sloper, 2010; Demouzon & Logerotlebrun, 1992; Lamar & De Cherney, 2009).

In-Vitro Fertilisation (IVF). This ground-breaking procedure was successfully used for the first time in the UK in 1978. The world's first test tube baby, Louis Brown, was born through this method. IVF involves a multistep process. When IVF becomes the course of treatment, the specialist will prescribe ovarian stimulating medication for the female partner. The ovarian stimulation is geared towards the production of multiple eggs. The eggs are then collected on a designated date. One method of collecting the eggs is through inserting a laparoscope through a small cut in the abdomen to draw off the egg-producing follicles. This procedure would be done under general anaesthetic. Alternatively, a needle is inserted through the abdomen and is then guided with an ultrasound to draw off the follicles, which requires a local anaesthetic. The eggs are then mixed with sperm in a laboratory and left to incubate for two days at normal body temperature. Approximately 60% of the eggs may be fertilised, provided that the biological material is healthy. One or two of the resulting embryos will be inserted into the uterus via a syringe. No anaesthetic is required for this part of the procedure. Any additional eggs that may have been fertilised may be frozen for future attempts. Implantation (attachment of the embryo to the lining of the uterus) will need to take place for a pregnancy to occur (Crawshaw & Sloper, 2010; Demouzon & Logerotlebrun, 1992; Lamar & De Cherney, 2009). This procedure is recommended to couples for several reasons.

IVF may be required if the male partner produces poor quality sperm, if the woman's body is producing antibodies to the sperm, or if she has blocked or scarred Fallopian tubes. Irregular ovulation and unexplained infertility are also reasons for IVF being recommended. IVF can be done using the male partner's sperm or donor sperm. When a man has a low sperm count, or produces sperm of poor quality or low motility, a technique called Intra-cytoplasm Sperm Injection (ICSI) can be useful. Here, the eggs and sperm are collected in the same manner



as for IVF. The woman's egg is placed in a dish and injected with a single sperm, to ensure that fertilisation takes place. The embryo is then transferred to the uterus at the right stage of development (Crawshaw & Sloper, 2010; Demouzon & Logerotlebrun, 1992; Lamar & De Cherney, 2009).

Donor eggs may also be used in cases where the female may not be producing eggs or if they are of poor quality. The donor eggs may be fertilised with the male partner's sperm or that of a donor. A select number of embryos are placed in the female's uterus and supportive hormonal drugs are administered to help maintain the pregnancy should conception occur. Egg donation is the only assisted conception technique available for women who are not producing eggs. Egg donation may also be considered when it is likely that a woman may pass on a genetic disorder to her children. Surrogacy and adoption are other options that may be considered when assisted conception fails. Donor embryos (with donor sperm and a donor egg) may be used in IVF procedures. These embryos may result from couples who are themselves undergoing fertility treatment and have produced several viable embryos during IVF or other methods. They may also be produced by fertilising donor eggs with donor sperm. Donor embryos are indicated when neither the woman's eggs nor the man's sperm can be used to achieve a pregnancy (Crawshaw & Sloper, 2010; Demouzon & Logerotlebrun, 1992; Lamar & De Cherney, 2009).

I provided a brief synopsis of some of the various treatment options that are currently available to couples presenting with fertility difficulties. What follows is a discussion on the provision and accessibility of fertility treatment in Africa.

The Impact of Limited Economic Resources on the Provision and Accessibility of Fertility Treatment in Africa

Up to now, African childlessness literature tells the tale of struggle: personal, couple, social, psychological, physical, spiritual and financialstruggle. Many infertile couples living in sub-Saharan Africa confront HIV/AIDS in addition to resource constraints, which further compound the barriers they face in their pursuit of parenthood (Huyser & Boyd, 2012). They are, in many instances, faced with healthcare systems that are directed towards addressing health problems such as malnutrition and infectious disease. Infertility is a non-life-threatening condition, and as such, is largely neglected by policy makers (Theoh & Maheshwari, 2014). When it comes to reproductive health, the focus is largely on family planning and education programs targeting prevention of pregnancy (Dyer et al., 2008; Huyser & Boyd, 2013;



Ombelet& Campo, 2007). This may be because many developing countries face the problem of high population growth rates (Ombelet et al., 2008). Access to and engaging in ART is expensive, and in many instances only accessible to the privileged few who can afford the financial costs involved (Huyser & Boyd, 2012; Huyser & Boyd, 2013; Huyser & Fourie, 2010; Ombelet et al., 2008; Theoh & Maheshwari, 2014).

There are many people around the world that decline treatment due to its associated costs. Theoh and Maheshwari (2014) examined the high treatment costs of IVF in divergent countries, revealing that three quarters of German couples declined to proceed with IVF treatment when it was recommended to them by specialists. One of the reasons was the expense of IVF; this even when the state provides German citizens funding of up to 50%. Although IVF costs and policies on the provision of treatment are variable across countries, the one universal element is that it is expensive in most parts of the world, including the United Kingdom and the United States (Theoh & Maheshwari, 2014). In Australia, IVF is publicly funded, with no limitations being imposed on the number of attempted treatment cycles, maternal age, the duration of sub-fertility, BMI, or smoking status. All that is required is a co-payment by patients for each treatment cycle. In 2010, the co-payment was increased by \$1 000, resulting in an approximate 25% reduction in IVF cycles across all Australian socioeconomic groups (Chambers, Hoang, & Illingworth, 2013). The UK employs strict restrictions on the provision of IVF treatment using public funding. The number of cycles funded is often limited for each person due to the costs involved (Theoh & Maheshwari, 2014).

As I sat with these statistics for a while I thought "what chance do people in resourcepoor communities have in accessing basic fertility care, never mind those who are recommended ART?" The South African Bill of Rights in the Constitution of the Republic of South Africa, Act No 108 of 1996, states that South Africans can "make decisions concerning reproduction". The legislation is progressive, yes, but this remains an "easier said than done" reality for many South Africans, as access to and the use of ART remains expensive (Huyser & Boyd, 2013). Public-funded fertility treatment is hardly available in many developing countries, and if it is, people face a "stand-in-line" type of system where waiting lists for treatment can stretch over years, coupled with treatment costs that are largely unaffordable for the majority of low-income earners (Huyser & Fourie, 2010; Theoh & Maheshwari, 2014). Not only are the conditions of the country impacting its people, but it also affects the public and tertiary ART units, as well as private practices in so far as their ability to adequately provide reproductive



health screening and fertility treatment possibilities. The running costs of an ARTprogramme can be very high. Procedural factors, microbial screening, sperm preparation, as well as facilities and supplies speak to and influence the financial costs of an ARTprogramme and therefore impact the South African public's ability to access these facilities (Huyser & Boyd, 2013).

Currently, South Africa has three main streams of ART service provision: one being public service academic-centred ART units. The second form of service provision is private undertakings with specialists utilising office-based or corporate pathology laboratories. The third provider of ART services are larger ART associates consisting of clinical and laboratory ART specialists. Approximately 28 national ART service providers are operational in South Africa. The question is: Can this meet the South African public's need? The area of specialisation and reputation of the service provider will impact on capacity, service provision, revenue generated and the population that utilises the unit. When it comes to national tertiary ART units, we currently have four in the country: two in Cape Town (Groote Schuur and Tygerberg/Vincent Palotti), one in Bloemfontein (Femspes Group), and one in Pretoria the REU at the SBAH. Cape Town and Pretoria's national tertiary ART units are entirely dependent on public funding (Huyser & Boyd, 2013).

In Chapter 1I focused closely on the REU at the SBAH from its inception, to the possibilities it creates. My research focuses on the aspects of fertility treatment experiences that were shaped by the REU and the findings of which can be found in Chapter 5.

Conclusion

This chapter surveyed the contributions the health sciences have made in understanding infertility, its causes, and treatment protocols. In it, I outlined the prevalence of involuntary childlessness in Africa, and the impact of economic resources on the provision and accessibility of fertility treatment in Africa. I also examined, in particular, the provision of fertility treatment options available in the South African public health context. In the subsequent chapter, I explore literature on the psycho-social-spiritual dimensions of involuntary childlessness to further illustrate the multidimensionality of infertility experiences.



CHAPTER 3: LITERATURE REVIEW II ExploringPsycho-Social-Spiritual Literature

I walked across an empty land I knew the pathway like the back of my hand I felt the earth beneath my feet Sat by the river and it made me complete...

I came across a fallen tree I felt the branches of it looking at me Is this the place we used to love? Is this the place that I've been dreaming of?

Oh simple thing where have you gone? I'm getting old and I need something to rely on So tell me when you're gonna let me in I'm getting tired and I need somewhere to begin

And if you have a minute why don't we go Talk about it somewhere only we know? This could be the end of everything So why don't we go Somewhere only we know?

"Somewhere Only We Know" (Chaplin, Hughes, & Rice-Oxley, 2004, track 1).³

³ Upon reflecting on fertility treatment experience, the lyrics of this song reminded me of couples' "known terrain" of subjective experience as it applies to fertility treatment. It is a place, "somewhere only we know", which I wished to access and become familiar with so that it would become somewhere I too would know.



Introduction

Technology truly amazes, befuddles, and amuses me. Amazes me, because on many levels, I cannot believe that human beings are capable of creating the technologies that they have; and just when the words "wow that is unbelievable!" have left my lips, the next wave of technology hits, and there I am saying the same thing again. The latter part of the 20th century saw increasing advancements in reproductive medicine. One of the most publicised, controversial and celebrated medical landmarks in reproductive medicine was the birth of the first human baby in 1978, resulting from IVF. Since the late 1970's, close to one million babies have been born worldwide with the help of one of the complex procedures that fall under the umbrella term of ART (Burns & Covington, 1999). Amazing! These technologies that have been created by human beings, for human beings, to have more human beings, are beyond remarkable.

Technology befuddles me, because my brain just does not seem wired to comprehend how technology really works and it amuses me, that no matter the conversations I have with gurus on their technology, I feel like a mere mortal who is at times, technologically challenged, if not phobic. It is an area of my life, that no matter the physical exposure I have to it, I struggle to grasp how it actually works. That frustrates me at times, because I want to understand when I am typing, like now for example, how my fingers pressing on the keys enables the letters to pop up on the screen. And for that matter, how does the screen actually work? The confusion that technology inherently represents for me provides an opportunity for reflection and personal learning in other spheres. It reaffirms to me that it is important that when I am working with somethingthat is beyond my realm of experience, I want to understand that something as much as possible. I have increasingly realised throughout this research process that it is not sufficient for me to have a rudimentary understanding of anything I work with. I crave an experiencenear understanding. The second learning is that this is not always entirely possible, where I am often confronted with unknown, muddy terrain, especially as it applies to therapeutic work. In the therapeutic context, I take the view that every client that enters a therapeutic space reads their personal journal to me, a little bit at a time, as they share their experiences. It is a privileged position, where curiosity is the co- therapist.

On the note of technology and the idea of journaling, I am reminded of the conversations I have had regarding the idea of "blogging" and how it seems to have made it increasingly possible for others to make public their personal journals. Blogs can be found on most subjects,



written by people situated all over the world. Their musings seem to be threaded with pearls of wisdom, coupled with a self-reflective quality, sharing with the world, the identity of the author. Despite my personal views on the practice of blogging, it got me thinking about how the authors' journaling practices when blogging, attracts commentary from others, and provides an additional context and avenue for people to story their experiences or feelings about a subject. The commentary opens up a space for people's views to be heard and to engage in critical discussions on the subject. In a blogging context, community discussions can take place in a virtual space, bringing together people from different parts of the world who display some kind of interest on a topic and who wish to express their views on the subject. This can all happen without anyone leaving their homes or offices. More mind boggling, is that virtual space can be engaged when people are away from their stationary computers, where mobile devices now provide a portable, easily available connection. Remarkable! Airports, hotels, bus stops, gyms, waiting rooms, lifts...so many spaces where conversations with others can happen without verbalising a word. Amazing, befuddling and amusing! I have noticed just how many people seldom look up when they are walking or driving now, attached to their mobile devices in what seems like a new yoga pose – the downward blog pose.

Technology really got me thinking about just how much society has developed and the possibilities for connectedness that can come with the technological advancements we have seen in the last ten years. Yes, there can be arguments that technology can have negative social consequences (Epstein, Rosenberg, Grant, & Hemenway, 2002; Kraut et al., 1998), but when it comes to the sharing of information and experience, it is amazing, befuddling and at times amusing just what kind information can be shared in seconds (Epstein, Rosenberg, Grant, & Hemenway, 2002; Valkenburg & Peter, 2009). So why am I talking about technology, blogging and society here? When thinking about surveying the psycho-social-spiritual literature on the experience of involuntary childlessness for couples and treatment, I initially thought of formal research contributions. Those that have been published in research journals, dissertations and theses, most of which can be found using the internet. As I initiated the review, I began wondering what are "non-sampled people" saying about their experiences and what are they not saying? Due to these questions, I decided to reserve a small portion of the literature review to surveying what researchers are saying about what is currently being shared in popular media, such as social media, blogs, and forums, to give additional insight into those experiences of people "interviewing themselves" on their experiences. I provide a snapshot of some of the experiences being expressed by people living in different pockets of the world who were not



clinic-sampled. After reading about research contributions made by those utilising non-clinicbased samples, I feel that future research could most certainly delve deeper into the cyber domain to obtain additional bio-psycho-social-spiritual insight into fertility treatment experiences.

Refocusing my thoughts back to the formal literature, I imagined the psycho-socialspiritual literature review in much the same manner that I personally envisage a blog or forum. While I will not be able to hear the voices of those who read and think about the literature conveyed here, I recognise that it will create commentary, discussions, and questions, all of which create a new thread in the conversation on fertility treatment experience. The third hermeneuticsis what I believe continues the trajectory of research, thrusting open more doors and with that, creating opportunities for new insights (Smith, Flowers, & Larkin, 2009). In my reading of the literature, I imagined each author's works as providing commentary on the experience of infertility from the perspective of their respective fields (i.e. psycho-social and spiritual narratives). This review serves to orientate the reader on the psycho-social-spiritual experience of infertility and the experience of fertility treatment. I have been acutely aware of how I have approached the literature reviews, in that I have dealt with the biomedical and psycho-social-spiritual traditions in two separate chapters in the thesis. I do not, however, view them as mutually exclusive. I feel constrained at times by the limitations of languaging the connectedness between all the different facets that are at play when a couple experiences infertility. While discussing one component, another could be discussed at the very same time. They are voices that speak to one another, but are seldom represented as such in the literature. As I reflect here, the 26 letters of the alphabet have at times felt like linear linkages when attempting to convey the 3-D picture of involuntary childlessness. In Chapter 7, the discussion draws together the findings of this research project and attempts to integrate the findings with the existing bio-psycho-social-spiritual literature attended to in Chapter 2 and Chapter 3 of this report. This literature review can be viewed as a continuation of the discussion that began with the medical sciences literature review, in Chapter 2. I commence the discussion with a broad survey of infertility literature, followed by a more focused discussion on treatment experience as this pertains to the research project in particular.

Psychological System

Infertility, as an area of interest, has maintained a dominant medical narrative in which physicians have typically been men, patients have been women, and the focus of treatment has



primarily been on the reproductive system (Marsh & Ronner, 1996). Throughout history, there have been various medical solutions to involuntary childlessness spanning across cultures. From antiquity, primitive medical treatments such as dietary modification, incantations and relics, vaginal treatments, and male sexual enhancement treatments, have been actively pursued and held influence for infertile couples seeking intervention (Covington & Burns, 2006). It can be argued that medical interventions for infertility became even more appealing to the childless couple at the end of the twentieth century with the dawn of ART. Despite men presenting with infertility as often as women, and despite that in many cases it can be both partners that experience fertility issues, throughout history and across cultures, women have unduly assumed the medical, social and cultural burden of a couple's childlessness (Covington & Burns, 2006). The emergence of ART has seen particular emphasis on the female partner being identified as the patient needing treatment, regardless of the cause of the infertility (Covington & Burns, 2006; Marsh & Ronner, 1996). Parallel to the medical advancements in the field of reproductive medicine was the emergence of interest in the psychology of infertility (Covington, 1995). From as early as the 1930's, the psychological impact of infertility has been documented in the literature, and with that, infertility counselling has emerged as a recognised profession and mental health speciality, which has taken many forms over the years (Covington, 1995).

Traditionally, mental health practitioners working in the field of reproduction would focus treatment on curing the patient's neurosis (with a specific focus on women), which in turn was believed to be pivotal in curing their infertility. Early psychological studies concentrated on individual psychopathology, infertility specific distress, and sexual dysfunction. During the 1970s, mental health practitioners began to provide more holistic treatment, offering psychological support, crisis intervention, and education to alleviate the stress of infertility and to improve the patient's quality of life (Bresnick & Taymor, 1979). Presently, the scope of the health professionals⁴ working in the field of infertility can be vast, including research, assessment, support, treatment and education (Covington, 1995; Boivin & Kentenich, 2002). The nature and course of the profession have advanced as more has been learnt both within the field of reproductive medicine and psychology.

⁴ I use the term "Health professionals" in the context of reproductive health, as an umbrella term to include all professionals that work in reproductive health, such as psychologists, counsellors, social workers, reproductive specialist and nursing staff.



Prior to providing current literary insights on infertility and treatment experiences, I would like to portray the meanderings that psychology as a discipline has taken when grappling with the issue. There have been attempts at better understanding the background story to the thoughts, behaviours, interactions and phenomenon associated with infertility (Covington & Burns, 2006). Specific theoretical frameworks have historically been based on specific theoretical perspectives or principles which have been applied to the field of infertility. These frameworks can aid researchers and health professionals by broadening our understanding of infertility experience, and therefore, assisting in developing and delivering treatment that is both supportive and minimises distress. In sharing an overview of theoretical frameworks here, my intention is not to provide the reader with an extensive plethora of information, but rather to briefly introduce you to how infertility experience has been conceptualised in the psychological literature over time. I have carefully considered highlighting only the main thrust of each contribution, as I continue to build a case for understanding infertility experience as a complex, bio-psycho-social-spiritual experience. What follows are psychological theories of fertility experience, which I intentionally approached in a manner that I hoped would read more as a narrative than an extensive exposé of psychological theory.

Psychological Perspectives

Psychogenic infertility theories. Historically, psychological frameworks have developed from *psychogenic infertility theories* (also referred to as the psychosomatic medicine approach) which were introduced in the 1930's, and grew in popularity during the 1950s and 1960s, especially in the United States. Psychological explanations of possible causes were considered helpful during a time where almost half of the infertility cases could not be accurately diagnosed or treated. Based on Freudian psychoanalytic approaches, these theories attributed the aetiology of infertility to the presence of psychopathology. Here, it was believed that unresolved conflicts and unconscious defence mechanisms caused sterility (Benedek, 1952). The focus was particularly on women's subconscious disturbances where it was believed that neurotic, conflicted feelings regarding adoption of a motherhood role, is what hindered conception. In Fischer's (1953) paper, she describes two personality styles that contribute to infertility in women: the weak, immature and overprotective type, and the ambitious, masculine, dominating, aggressive, career orientated type. The former was believed to have difficulty separating from her mother, or had difficulty with direct expression of her anger, or had an abnormal fear of sex, pregnancy, labour and motherhood, which prevented conception. The ambitious women were believed to be infertile because if they were to become



pregnant it would mean they would then be accepting of their sexual feelings and would be required to give up the fantasy of remaining a child (Rothman, Kaplan, & Nettles, 1962). The infertile man, on the other hand, was believed to have had domineering and controlling mothers, who created anxiety within their sons as a result of their own sexual difficulties (Belonoschkin, 1962). Furthermore, it was believed that conflicted feelings about fatherhood caused infertility (Rubenstein, 1951).

Psychological consequences theories. As medicine developed and was more successful in diagnosing and treating reproductive difficulties, the psychogenic theories became less popular, ushering in the next phase of psychological frameworks. In the 1970's, the *psychological sequelae* or *psychological consequences theories* emphasised the experience of infertility and fertility treatment as representing an all-encompassing and emotionally difficult process for individuals and couples. Here, infertility was the consequence and not the cause of involuntary childlessness (Greil, 1997; Menning, 1980). This model took a broad view of involuntary childlessness, looking at the interrelationships of the couple, family, society and medicine, whilst integrating various theoretical models such as developmental models, crisis theory, bereavement models and the development of a stage theory of infertility (Menning, 1980). Infertility was described as a major life crisis involving stress and grief, as the inability to procreate impaired the completion of adult tasks of intimacy and resultant conception. This created a period of disequilibrium, which could potentially lead to maladjustment, or provided an opportunity for positive growth and creating homeostasis for the couple.

Alongside this, infertility evoked feelings and responses that mirrored a predictable pattern similar to those seen in the stages of bereavement: recognising the loss; assignment of meaning to the experience; acceptance and rising above the experience of loss (Menning, 1980). Although the psychological consequences-approach has been criticised for applying a medical model to complex psychosocial experience of infertility thereby failing to recognise social and cultural factors that have influence in infertility experience and treatment, as a model it did recognise the importance of the psychosocial aspects of infertility, which was particularly useful for mental health practitioners and medical personnel, working in the field of reproductive health. It also highlighted adjustment to infertility as a problem that warranted further study (Greil, 1997; Stanton & Dunkel-Schetter, 1991b).



Psychological cyclical model. In response to the critique, a number of approaches were suggested, one of which includes the *psychological cyclical model* (Van Balen, 2002). Proponents of this model view involuntary childlessness as creating increasingly high stress levels, which in turn causes physiological changes that can affect the efficacy of fertility treatment. Psychological distress, therefore, has a biological consequence that can influence conception (with or without medical treatment). What was absent in this model, was that there was no attention paid to the stress levels of the male partner, nor was there clarity on which levels of stress would be counterproductive for individuals in specific circumstances (Wischmann, 2003).

The psychological outcome approach further developed the psychological cyclical model. Here it is defined as a biopsychosocial perspective, which integrated the mind-body and family system in recognising the multifaceted factors that have an influence on conception and treatment outcomes. The focus is on the psychosocial response to infertility treatment of individuals, couples and families and takes into account the psychological interventions that impact treatment outcomes (Wischmann, Stammer, Scherg, Gerhard, & Verres, 2001). Much in the same line, the *psychosocial context approach* addressed infertility as an experience that occurs within a social institution (e.g. marriage) and context (e.g. religion). This theory recognised that infertility is not solely an individual psychological experience, but is social, occurring within the context of the couple's social milieu and as such is better understood as a "process" rather than an "event". Furthermore, as a global approach, it attempts to understand and describe the psychosocial phenomena of infertility and treatment, looking at culture, religion and other environmental factors that can influence infertility experience for people. The psychosocial context approach examines inequality in the availability and access to fertility treatment, and recognises that cultural and religious factors can have an impact on the psychosocial responses to infertility. Moreover, the psychosocial context approach recognises cultural responses to reproductive tourism (crossing borders for fertility treatment) as well as the acceptability of treatment and acceptable alternative solutions to creating a family (e.g. adoption). Both the psychological outcome approach and the psychosocial context approach provide an increased understanding of the multifaceted factors that can influence infertility experience. In turn, it increases healthcare professionals' knowledge of clinical issues that can inform the provision of meaningful therapeutic support (Greil, 1997). One such issue is of grief and loss, addressed specifically in the grief and bereavement approaches (Kuchenhoff, 1999; Lukse & Vacc, 1999).



Grief and bereavement approaches. When utilising these approaches to understand infertility experience, infertility is understood as involving a sense of loss, whether it is a distinct sense of loss at the beginning of fertility treatment, or a gradual accumulation of losses experienced throughout the course of treatment. Losses may include, but are not restricted to: health, parenthood role, physical and psychological well-being, self-confidence, or the loss of privacy and physiological autonomy, to name but a few. Interpersonal relationships too may be redefined, or forever lost, and with that, a grieving process may ensue. According to Lukse and Vacc (1999) and Kuchenhoff (1999), the grieving process in the infertility experience may involve typical responses, such as shock, disbelief, anger, blame, shame and guilt, a diminished sense of control and self-esteem, chronic bereavement, anxiety, and depression.

Interest in infertility-specific bereavement sparked Burns and Covington (1999) to develop the *keening syndrome of infertility-specific grieving*. Here they describe the keening as referring to the Irish custom of grieving where women typically weep, while preparing the deceased body for burial, and men typically watch in sombre silence, sharing alcoholic drinks which are usually associated with the "Irish Wake". In the context of infertility, the keening syndrome of infertility-specific grieving refers to individual responses to grieving within the couple system, highlighting gender differences in the grieving process. Women actively weep, often assuming the role of "primary mourner", while men watch, and may emotionally distance themselves from the couple's shared loss. Explanations for the gender differences in grieving have been that women's intense emotional reactions may be related to how treatment is disproportionately geared more towards women than men, or it may be a process-in-action of cultural patterns unfolding in which women feel responsible for the couple's emotional wellbeing and express the couples' grief more verbally than their male partner. With that being said, men may be forgotten in the grieving process due to verbalising their grief less or more subtly than their partner, or it may be that they find it difficult to express their grief as openly as their female partner. According to the authors, a couple's inability to acknowledge and process appropriately, can have a long-term impact on the couple's ability to adjust to infertility, and may negatively impact on the couple's capacity to make treatment-related decisions or evaluate alternative options to building a family (Burns & Covington, 1999; Covington & Burns, 2006).

Chronic infertility-specific grief model. Objections to applying traditional infertilityspecific grieving approaches arose due to its inability to attend to and address the chronic nature



of infertility. Unruh and McGrath (1985) proposed a *chronic infertility-specific grief model*, depicting infertility as typically involving many losses over an extended period of time, thus resulting in chronic sorrow where infertility-specific grief may never be completely mourned and accepted. Harvey (2002) extends this idea further by describing infertility as a type of disenfranchised grief, where infertility is experienced as a loss that may lead to intense grief, although others may not recognise it as such, and may not be viewed as justifiable in the eyes of others. Disenfranchised grief is considered complicated bereavement due to the absence of the usual support systems that would usually facilitate healing. Furthermore, social stigma may prevent individuals and couples' from acknowledging and sharing their loss, silencing and isolating individuals in their grief. One can ask then, how are individual identities shaped by infertility?

Integration of infertility into the sense-of-self-model. Olshansky (1987) developed the integration of infertility into the sense-of-self-model, which recognises infertility as an experience capable of altering an individual's identity and sense of self. Infertility alters an individual's sense of self through creating or amplifying a sense of deficiency, hopelessness and feelings of shame. Infertility results in altered self-concepts and self-images, which are experienced by both men and women, albeit that it may be felt and exhibited differently. According to Olshansky (1987), women may feel inadequate due to their inability to fulfil their own and socially designated motherhood roles, while men may feel ashamed, inferior and inept. The internalisation of infertility experience is viewed as instrumental in managing the narcissistic wounds, as well as the loss of self that can be created by infertility (Leon, 1990; Olshansky, 1987). The main thrust of this theory is that individuals must integrate infertility into their sense of self and self-identity, thus transcending the experience through overcoming and reconciling the identity of the self as infertile (Olshansky, 1987). Kikendall's (1994) selfdiscrepancy theory addresses identity issues in infertile men where it is argued that infertility signals a personal identity crisis for women where they are conflicted between their ideal sense of self as a mother and their real sense of self as infertile.

Stress and coping theories. Recognising the importance of stress and consequent psychological adjustment to infertility and treatment, *stress and coping theories* developed. The first reference to infertility as a *stressor* was by Taymor and Bresnick (1979), who acknowledged and identified that there is an interplay between physical conditions which predispose individuals to infertility, fertility treatment, societal reactions, and individual



psychological characteristics. Application of stress and coping theory to infertility identifies infertility as stressful in respect to what individuals find to be particularly stressful about situations, such as ambiguity, unpredictability, and the uncontrollability of the situation. Stanton and Dunkel-Schetter (1991a) conceptualised infertility as a life crisis, typically experienced as an insolvable problem which threatens the achievement of personal life goals and is emotionally strenuous. They add that couples view infertility as carrying both the potential for harm and benefit, as well as being a process where individuals may feel a sense of loss of control and on the flip side may feel the stressor has controllable elements. Harm in that they may need to confront the loss of the desired parenthood role, and benefit in that the process of infertility may potentially create closeness within the couple relationship. Individuals may feel a sense of utilising treatment, but on the other hand, may feel a sense of loss of control as successful pregnancy is not within their control (Stanton & Dunkel-Schetter, 1991b).

Stress may be experienced as an acute, time-limited crisis which may involve certain coping strategies in order to adapt to the crisis (for example, when the reproductive specialist delivers a diagnosis which has caused the infertility). Infertility can also be experienced as a chronic stressor, where fertility treatments, emotional distress, and events accumulate over time which requires activation and utilisation of coping strategies to allow adjustment and adaptation and to ensure emotional and marital equilibrium in the face of whatever the outcome may be (Stanton & Dunkel-Schetter, 1991b). Stress and coping theory illuminates the infertility may be perceived as stressful and the factors that may assist or hamper adjustment in the face of those stressors. Furthermore, the theory provides scope and insight into what therapeutic interventions may be beneficial in reducing stress, assisting adjustment and adaptation in the hopes of elevating the experience of stress and enhancing treatment outcomes (Covington & Burns, 2006).

Social construction and stigma theories. Theoretical frameworks have been developed and employed to understand infertility as a cultural, religious and existential experience. Singer and Hunter (2003) posit that a sense of self as infertile is constructed within the context of interpersonal relationships, such as family systems, culture, values, religion and language. *Stigma theories* are applicable to both gender-specific infertility and infertility-specific individual distress within cultural contexts (Covington & Burns, 2006; Goffman, 1963;



Sandelowski & De Lacey, 2002). Stigma can be experienced by both men and women, where a self-perception of diminished self-esteem, a sense of loss, and failure to fulfil pronatalist norms extends to the social identity of the person, overshadowing other areas of the person's identity and perceived achievements (Goffman, 1963). Culturally universal responses to infertility for both men and women have reportedly been feeling a sense of inadequacy, inferiority, shame, guilt, worthlessness and feeling a sense of imperfection or possessing an invisible disability (Matthews & Matthews, 1986; Miall, 1985; Nachtigall, Tschann, Quiroga, Pitcher, & Becker, 1997). In studies that have examined male-factor infertility, men have reported experiencing more stigmatisation than when their partner is the source of the infertility, whereas women seem more stigmatised by infertility irrespective of the diagnosis (Nachtigall et al., 1997). Stigma may create social isolation in some cultures and communities (Whiteford & Gonzalez, 1995), where social stigma may be experienced as failure to fulfil expected parenthood norms, which impacts negatively on personal identity. Infertility can also be experienced as a transformative process, where individuals acknowledge their sense of loss and allow themselves to grieve the loss of reproductive function and parenting roles (Gonzalez, 2000).

Family system theories. Infertility experience seems to move beyond the individual and couple system, permeating the extended family in divergent ways. *Family systems theorists* describe infertility as an *intergenerational family development crisis*, which prevents parents from becoming grandparents and siblings from becoming aunts and uncles. Infertility can be experienced and viewed as a crisis in *family developmental genealogy*, impeding the family's ability to grow (Daly, 1999). The family life-stage model posits that identity confusion and role adjustment leads to family stress and crisis (Matthews & Matthews, 1986). Infertility then represents a transition to non-parenthood, highlighting the couples' inability to make the transition to parenthood, leading to confusion and uncertainty regarding life tasks, roles and boundaries in their relationships.

According to family systems theorists, the disparity between the biological and social condition of involuntary childlessness is an important determinant in how individuals and families will experience and deal with infertility. Ambiguity can arise in the couple system and that of the extended families, as family relationships and roles are impacted by the child who is so desperately and is, therefore, experienced as psychologically present, but is physically absent. The blurring of the boundaries can create ambiguity in the marriage and extended



families, which can be experienced as painful as the longed-for child becomes idealised over time, representing idealised portions of each other. On the flip-side, the continued childlessness may be perceived as being caused by the faults of themselves or their spouse. Rigid boundaries may develop in response to infertility in an attempt to secure their privacy, which has the potential to lead to isolation from friends and family, whereas other couples may create boundaries that are easily permeated, where too much information is shared with others or a partners' displays a disregard for their spouses' boundaries (Burns, 1987).

Stage theory. Blenner's (1990) *stage theory of infertility*, isolates and describes the stages of infertility couples move through, from pre-diagnosis to post-treatment, identifying the passage from one stage to the other. The passages from one phase to another are based on three concepts: engagement, immersion and disengagement. Blenner (1990) describes the stages within these concepts: Firstly, individuals or couples experience a dawning of awareness, where they realise that something is wrong. Secondly, they confront a new infertile reality. Thirdly, the couple enters a stage of hopefulness and one where they are committed to achieving a successful pregnancy. Fourthly, the couple enters a stage where they increase treatment, in the hopes of achieving success. Fifthly, after an unsuccessful attempt, the couple begins to surrender control. Sixthly, the couple decides to terminate treatment; and lastly, enters a stage where they focus on other things in order to disengage.

Similar to Blenner's stage theory, Diamond (1999) identified five phases of infertility. In the Dawning phase, couples become more and more aware that there is a fertility issue and seek medical advice. The couple begins *mobilisation* as they engage in diagnostic treatment. A diagnosis of infertility can lead to shock, disbelief and denial. As the couple undergoes increasing intensive testing and fertility treatments, *immersion* can be one of the most complex and physically and emotionally demanding phases, as the couple may feel like they are in a phase of not yet being parents, which prevents them from actualising their parenthood role. For some, the couple may face family-building alternatives they never believed they would have to, such as the probability of requiring donor gametes, donor embryos or adoption. The Resolution phase involves a triad of overlapping phases: the phase of ending medical treatment, followed by mourning the loss of not having conceived, and lastly refocusing on other possibilities such as considering adoption or childlessness, for example. Lastly, the Legacy phase of infertility acknowledges that infertility experience does not end at the point of considering and taking up



an option, but is cognisant of the resultant consequences of infertility on the marriage, sexual relationship and parenting difficulties that may emerge in response to infertility.

Undoubtedly, the literature recognises infertility as a distressing experience that has the potential to threaten individual, marital, family, and social stability. The psychology of infertility, in the midst of diverse populations and circumstances, requires the identification of contrasting responses and unique circumstances, which can influence therapeutic approaches and interventions. Cultural-sensitivity when working in the field of infertility can provide the psychologist, social worker or counsellor, with much-needed insight when designing and implementing interventions. Provision of culturally-sensitive fertility counselling requires specialised skills and adaptability, legal and ethical prowess, and dedication to continued learning and education in the field of infertility. Provision of therapeutic services that sets out to improve both patient care and satisfaction, rests, in my opinion, on mobilising collaborative, multidisciplinary reproductive healthcare. A tall order for South Africa? Perhaps, but it is possible in a treatment facility such as the REU at the SBAH.

I shift focus from the theoretical underpinnings that inform our psychological understanding of infertility experience, to a synopsis of research contributions on the experience of involuntary childlessness. I move on to a focused discussion on the experience of fertility treatment and conclude the psychological narratives with a critique of the research to date.

Research Trends

Broadly speaking, different disciplines have demonstrated an interest in infertility as a researchable topic bringing with them, differing research trends. We can examine research contributions from methodological, geographical, gender, topic and context related perspectives. I briefly highlight each separately, whilst being mindful that each aspect discussed encompasses elements of the other. For example, in highlighting research contributions from different countries, one must acknowledge that the research is not always homogenous, often representing different methodological approaches and areas of interest, from the same geographical areas.

In general, many countries have shown interest in involuntary childlessness, for example, the United Kingdom (UK) (Charlish & Davies, 2007; Pfeffer & Woolett, 1983; Redshaw, Hockley, & Davidson, 2007; Touroni & Coyle, 2002), the United States of America



(USA) (Greil & McQuillan, 2004; McQuillan, Greil, White, & Jacob, 2003; Shreffler, Greil, & McQuillan, 2011; Stephen & Chandra, 2000), India (Mahajan, 2008; Mahajan et al., 2009), Italy (Ardenti, Campari, Agazzi, & La Sala, 1999)Hong Kong (Meyer, 2001), France (Demouzon & Logerotlebrun, 1992; Tain, 2003), Denmark (Nyboe, Andersen, & Erb, 2006; Schmidt et al., 2003), Taiwan (Lee, Sun, & Chao, 2001; Su & Chen, 2006; Yang et al., 1991) and sub-Saharan Africa (Sundby & Jacobus, 2001) are a few examples of countries who have made valuable research contributions.

Greil, Slauson-Blevins, and McQuillan (2010) identify two distinct methodological streams in their review of the literature on the experience of infertility. The first was identified as a quantitative, clinically orientated, research approach which has traditionally centred on gathering data from patients receiving ARTtreatment, and has been characterised by quantitative analysis of results derived from standardised psychological assessment tools. The goal of these studies has largely been to assess the needs for psychological counselling and to improve service delivery in treatment facilities. Quantitative studies have seemed to dominate the field of infertility research both internationally (Ardenti, Campari, Agazzi, & La Sala, 1999; Charlish & Davies, 2007; Demouzon & Logerotlebrun, 1992; Greil, 1997; Greil & McQuillan, 2004; Mahajan, 2008; Meyer, 2001; Pfeffer & Woolett, 1983; Shreffler et al., 2011), and locally (Dyer et al., 2005; Dyer et al., 2009; Mabasa, 2003).

The second trend identified in the literature is a qualitative tradition, which too has spanned international and local borders (Dancetet al., 2011; Greil, 1997; Redshaw, Hockley, & Davidson, 2007). Qualitative research in the area of infertility has tended to focus on the experience of infertility for men, women and couples respectively. These studies have primarily attended to understanding the experience of infertility for people and the social contexts that shape their experiences. Greil (1997), Henning, Strauss, and Strauss (2002), andPasch and Christensen (2000) identified limitations within the social-scientific research on infertility, citing: small sample sizes, poor sampling methods, the use of non-standardised measures, and lack of control groups as being some of the salient shortcomings.

In addition to the two, aforementioned traditional methodological trends, there is a third facet of research which could potentially provide fresh insights on infertility experience: researching non-treatment seekers. Greil, Slauson-Blevins, and McQuillan (2010) surveyed literature that was published between 2000 and 2010, making an interesting case for the need



for research to step outside of the pervasive trend of sampling only clinic-based patients who are receiving fertility treatment. They maintain that current literature does not adequately provide insight into the experience of involuntary childlessness and the lack of treatment seeking behaviours of those who do not seek medical intervention. With a lack of research of non-treatment seekers, it is impossible to understand why some seek treatment while others do not, or why those who would be interested in seeking medical intervention, do not. We have seen some studies that have made headway in researching non-clinic based samples. However, these studies have more often than not, been quantitative in nature, utilising national survey data of large samples, to improve the generalisability of their findings. An example of this trend is King's (2003) research conducted in the USA, which utilised infertility status data for women, which was derived from the National Survey of Family Growth, and assessed whether treatment seekers and non-treatment seekers met the criteria for anxiety. A study conducted by McQuillan, Greil, White, and Jacob (2003) of 580 minority women in the USA, examined the relationship between infertility and distress and found that involuntary childlessness is associated with significant distress. Information obtained from a nationally representative sample of women who had given birth in the UK was utilised in research conducted by Redshaw, Hockley, and Davidson (2007), to determine their reactions to infertility treatment. They found that women reported that being treated with respect and dignity was a priority, and being provided with information and support, were further important components to fertility treatment. Patients reported that when professionals acknowledged and normalised their feelings, especially in situations where the outcome was uncertain, this reduced their emotional discomfort. Internet surveys have also been utilised in studies wishing to obtain insights into people's utilisation of the internet for infertility support (Epstein, Rosenberg, Grant, & Hemenway, 2002), and treatment seeking behaviours (Bunting & Boivin, 2007). These studies found that people experienced the internet as useful in providing information and emotional support, but on the flip side, could be used inappropriately to socially withdraw. Venturing outside of the home to seek medical advice for conception difficulties was mediated by the questions women had about their own fertility and it was reported that negative reactions substantially delayed treatment-seeking in 20% of women (Bunting & Boivin, 2007).

Whilst there are moves towards illuminating the experiences of non-clinic based individuals, a large proportion of the research has been dedicated to generalising findings derived from national surveys to the larger population. What about the unique views of men and women whose views do not align with the dominant trend? What can we capture



qualitatively? What about the views of those living in developing countries, where literacy and accessibility may impede research on a grand scale? What about the views of men and women in developed countries? I am not the only researcher having considered these questions, with many researchers venturing into cyberspace to conduct qualitative research using data derived from online platforms, for example. Hanna and Gough (2016) focused on the male experience of infertility using posts from a men's only online infertility discussion board. Their research found that men found value in sharing their emotional difficulties of infertility with other men, exchanged coping strategies, and discussed the impact that infertility has had on relationships. In general, the forum provided a space for men to express, normalise and in some cases, mobilise (in the form of coping strategies) in the face of fertility struggles.

The realisation that all research has limitations dawned on me in my second year of undergraduate studies. This awareness was amplified for me during the process of not only reviewing current literature, but more so in the writing of this research report. I have become increasingly aware of the possibilities, limitations and new avenues for research on this topic. One such possible avenue for the future may be to gauge non-clinic based views of those echoed in popular media. Asking what are newspapers, magazines, radio, social media and whatever other galaxies that are made available in cyberspace, saying about infertility experience? And with that, are there differences in social media views where, for example, a virtual venue is created allowing different cultures to speak on the same experience? Can these platforms provide valuable resources for research, and provide an opportunity for critical consumption and interpretation of information? It has certainly provided food for thought as I have dived deeper into the psychosocial possibilities for research and has elicited curiosity for me to perhaps pursue research in this direction in the future.

Coming back to current research, one can identify differences in sampling trends. Gender bias seems to be a pervasive sampling tendency in both international and local research. International examples of this sampling trend can be seen in studies that solely focus on female experiences of infertility. Countries such as France (Demouzon & Logerotlebrun, 1992); the UK (Charlish & Davies, 2007; Pfeffer & Woolett, 1983; Redshaw, Hockley, & Davidson, 2007; Touroni & Coyle, 2002); the USA (Greil & McQuillan, 2004; Shreffler, Greil, & McQuillan, 2011); India (Mahajan, 2008; Mahajan et al., 2009); Italy (Ardenti, Campari, Agazzi, & La Sala, 1999);Hong Kong (Meyer, 2001), and sub-Saharan Africa (Dyer, Abrahams, Hoffman, & Van der Spuy, 2002; Dyer, Abrahams, Mokoena, Lombard, & Van der Spuy, 2005; Sundby &



Jacobus, 2001; Sundby, Mboge, & Sonko, 1998) produce research which displays this sampling trend.

In South Africa (SA), the field of psychology has tended to follow a similar sampling trajectory, with research focusing solely on the female partner (Dyer et al., 2002; Dyer et al., 2005; Van Breda, 1989). Men's' experiences of fertility treatment, for example, has been researched extensively both locally (Dyer et al., 2004; Dyer, Lombard, & Van der Spuy, 2009), and internationally (Baluch, Nasseri, & Aghassa, 1998). One may argue that the gender bias that seems to dominate the psychological literature may be better accounted for by the research question and goals of the research. Thus, if the focus of the research was to gain insight into the experience of fertility treatment for females, it makes sense to sample only females. As I see it, all research can have the potential to not only illuminate the topic at hand, but shines alight on other researchable areas, paving the way for innovative research.

Much like a tapestry, gender is interwoven throughout my discussion of the literature as I attend to different elements of infertility experience. At times, I discuss men and women's experiences in isolation, and at other times, the male and female experience is discussed simultaneously as it applies to a psychosocial construct. For example, when discussing patriarchy in the portion of the thesis dedicated to the social narratives, both male and female voices speak to the concept, as it applies to each gender. However, when reporting on research that has centred on the male or female experience of involuntary childlessness specifically, I have attended to each separately in keeping with the literature, before consolidating and critically considering what the literature is telling us on the experience of infertility.

I conclude my engagement with psychological narratives with a focused discussion on fertility treatment experiences. The discussion highlights the dominant themes in the literature, drifting between female, male and couple responses to and experiences of, fertility treatment and concluding with a critique of the psychological literature.

Experiencing Fertility Treatment

Over the last 80 years, extensive research has been conducted on the psychological experience of infertility and its treatment. The dominant narrative that has undoubtedly unfolded in the literature is that involuntary childlessness is experienced as stressful for individuals and couples across the globe, as the consequences of infertility are far reaching



(Charlish & Davies, 2007; Wirtberg, Moller, Hogstrom, Tronstad, & Lalos, 2007). Societal and personal suffering are often juxtaposed by the hope that fertility treatment can offer couples today (Cousineau & Domar, 2007). Consistent with stress and coping theories research shows that emotional responses such as distress, stigmatisation, loss of control and a disruption in the developmental trajectory of adulthood, is starkly contrasted by the backdrop of hope that fertility treatment offers couples, and would support the notion that infertility experience and treatment for infertility may be experienced as stressful. The experience of infertility as stressful may be further amplified for those couples who may know that fertility treatment is available, but is out of reach due to poor resources, lack of affordability, and/or access difficulties (Cousineau & Domar, 2007; Ombelet & Campo, 2007; Ombelet, Cooke, Dyer, Serour, & Devroey, 2008; Sexton, Byrd, & Von Kluge, 2010; Stanton & Dunkel-Schetter, 1991a; Taymor & Bresnick, 1979). According to Cousineau and Domar, (2007), more and more evidence supports that there is a connection between the experience of distress during fertility treatment, patient drop-out rates, and with that, pregnancy rates, although the exact association between stress and fertility outcomes is not known. The work of Sexton, Byrd, and Von Kluge (2010) explored the association between resilience, distress and coping behaviours in women, and found that resilience was negatively impacted during an active engagement in fertility treatment. In this regard, authors have put forward recommendations centring on improving patient care by offering psychosocial interventions that focus on improving coping skills (Sexton, Byrd, &Von Kluge, 2010), as well as advocacy of continuous psychological research in a continued attempt to enrich our understanding of the intricacy's in emotional responses to treatment alongside the development and advancement of fertility treatment. Further research may provide more insight into the subsequent impact distress can have on fertility outcomes, as well as to guide the therapeutic practices of practitioners engaging in supportive work with people who face infertility (Cousineau & Domar, 2007; Sexton, Byrd, & Von Kluge, 2010).

Traditionally, infertility has been viewed as a *female* problem, and with that, a popular inference that may be made is that women may be expected to suffer greater psychological distress than men. Berg, Wilson, and Weingartner (1991) investigated whether there seemed to be gender differences in the psychological effects associated with infertility treatment. Their research findings did not support the expectation that women experience higher distress levels than men, where in fact, no gender differences were noted in the level of emotional strain experienced, or in the experiences of marital adjustment and sexual satisfaction. Where gender differences were noted, however, were in *factors* associated with psychological distress. This



suggested that while the level of strain was relative, infertility is experienced differently for men and women, where their sex-role identification (masculinity and femininity) seemed to have a greater relationship to the experience of distress than gender. Conversely, other literary contributions on fertility related distress refute the notion that distress is experienced equally for both genders, maintaining that women experience treatment as more stressful than men (Abbey, 2000; Anderson, Sharp, Rattray, & Irvine, 2003; Edelmann & Connolly, 1998; Henning, Strauss, & Strauss, 2002; Holter, Anderheim, Bergh, & Moller, 2006; Monga, Alexandrescu, Katz, Stein, & Ganiats, 2004; Slade, O'Neil, Simpson, & Lashen, 2007). Women seem to be more treatment-orientated than men, invest more into having children (Pasch & Christensen, 2000) experience more stigma (Slade, O'Neil, Simpson, & Lashen, 2007), and seem to find intense difficulty in surrendering their intended parenthood role, more so than men (White & McQuillan, 2006). International and local studies have documented that women feel a sense of failure when a treatment cycle is unsuccessful, and with that, they revisit the trauma of acknowledging the presence of a fertility problem (Agostini et al., 2011; Dyer et al., 2005; Shreffler, Greil, & McQuillan, 2011).

Quantitative studies of women and men experiencing involuntary childlessness confirm that whilst they do not exhibit a higher tendency towards psychopathology, they are more likely to experience higher levels of distress than comparison groups (Monga, et al., 2004). Women who experience infertility display higher tendencies towards depression and anxiety than those who conceived naturally (Oddens, Den Tonkelaar, & Nieuwenhuyse, 1999), while several IVF studies found that women's distress levels did not differ significantly from norms. Equally controversial, studies of men report mixed results showing on the one hand higher scores for anxiety (Baluch, Nasseri, & Aghssa, 1998) and depression in men, especially in cases of malefactor infertility (Baluch, Nasseri, & Aghssa, 1998; Folkvord, Odegaard, & Sundby, 2005), whilst other findings show that men dealing with couple infertility do not differ from controls in respect of psychological wellbeing (Monga, et al., 2004). A longitudinal study conducted in Denmark concluded that men, regardless of the source of the infertility, experience infertility as stressful (Peronace, Boivin, & Schmidt, 2007). There does not seem to be a link between the diagnosis of infertility and stress levels (Edelmann & Connolly, 1998; Holter, Anderheim, Bergh, & Moller 2007; Wischmann et al., 2001). Polarities in the literature extend to the experience of distress related to the length of treatment, where on the one hand research shows that the length does contribute to higher stress levels (Chiba et al., 1997; Nasseri, 2000), whilst on the other hand studies show that the length of treatment is not related to stress levels



(Anderson, Sharp, Rattray, & Irivine, 2003). IVF studies of men and women have highlighted that stress levels vary with the stage of treatment (Ardenti, Campari, Agazzi, & La Sala, 1999; Boivin et al., 1998). Studies of women utilising ART, show that it is the outcome of the treatment that gives rise to increased stress (Lok et al., 2002; Verhaak et al., 2007), with most women adjusting to unsuccessful treatment outcomes (Beutal et al., 1998; Verhaak et al., 2007).

When examining the literature on distress and coping strategies among infertile individuals, it seems that stress is lessened considerably when individuals have access to and utilise social coping resources, are in growth-fostering relationships, have the support of their partner and have family support (Gibson & Meyers, 2002). Women who view infertility as a challenge rather than a loss were less distressed (Hansell, Thorn, Prentice-Dunn, & Floyd, 1998). Those who link their future happiness with becoming a parent, show higher levels of distress (Brothers & Maddux, 2003), which concurs with White and McQuillan's (2006) study that found women who struggled to surrender their motherhood role experienced high levels of distress. Kantor's (2006) study of South African women's experiences of involuntary childlessness found that women felt a sense of deficiency and abnormality, as they could not fulfil their individually and socially desired motherhood role. Women seem to mediate their stress levels by seeking social support, escaping or avoidance, application of plan-orientated problem-solving and positive reappraisal (Jordan & Revenson, 1999). A study by Pasch, Dunkel-Schetter, and Christensen (2002) found that men experienced negative effects when their wives wish to talk about their experiences. Conversely, couples' have reported feeling that infertility has created closeness within their relationship (Greil, 1991; 1997), and in talking about their experiences, men feel a sense of infertility as a shared experience and in turn, seemed to strengthen their relationships (Webb & Daniluk, 1999). On the flip side, literature also talks to infertility as having a negative impact on marital relationships, threatening marital stability. The extent of the impact of infertility on the marital relationship can be dependent on the sociocultural context. In contexts where women's roles are linked with motherhood, and marriage is defined in terms of producing offspring, infertility can have a greater negative impact on the couple relationship (Sundby, 1997; Wirtberg et al., 2007). This is supported by research conducted in the developing world (which I attend to in the sociological narratives section of the literature review).

Qualitative literary contributions draw an equally conflicted picture on the differences in the ways men and women experience infertility treatment. According to Greil (1991) women



seem to experience an injury to their identity, while men experience infertility indirectly, through the consequence and impact it has on their wives. This sentiment is supported by Beutal, et al. (1998), who described infertility as having a greater impact on women's daily lives and therefore increased their need for support, whilst husbands felt a sense of responsibility for the couple infertility. Women are more likely to experience changes in mood and report feelings of jealousy of those who are fertile, while men feel a sense of loss of control and worry about their partner (Hjelmstedt et al., 1999). Fisher and Hammarberg (2012) state that psychological and social aspects of infertility in men have often taken a backseat when examining the literature (Fisher & Hammarberg, 2012) and advocate that continued research on the male experience of infertility can provide an opportunity for psychologically informed clinical care.

Fisher and Hammarberg (2012) conducted a structured literature search examiningmen's experiences of infertility, the psychological and social aspects of diagnosis, the experience of ART treatment, and the experience of unsuccessful treatment. Although the studies differed in conceptualisation, design, context and data collection methods, the findings were, for the most part, consistent. The literature conveyed that men express a desire for parenthood that is similar to those of females. Furthermore, the diagnosis of infertility, and commencement of treatment was associated with raised infertility-specific anxiety and unsuccessful treatment can lead to the experience of lasting sadness. Despite this, rates of clinically significant mental health problems among these patients were no higher than those of the general population.

Fisher and Hammarberg (2012) describe infertile men who socially isolate themselves, as presenting with an avoidant coping style and view stressful events as overwhelming. These men are considered more vulnerable to experiencing severe anxiety, than men who do not exhibit these characteristics. The data showed that men prefer oral treatment information to writteninformation and show a preference for emotional support from infertility clinicians, as opposed to receiving support from mental health professionals, self-help support groups or friends. Fisher and Hammarberg's (2012) review of the literature identified pervasive gaps in knowledge about factors governing treatment seeking, continuing with treatment, and deciding to terminate treatment. They also identified gaps in the literature when it comes to men's experiences of invasive procedures, experiences of parenting after assisted conception, adoption and infertility-related grief and shame among men.



In Africa, infertility has traditionally been described as a women's issue. However, women and men, in their reproductive years who are faced with the struggle to conceive a child, are increasingly seeking treatment (Anderson, Sharp, Rattray, & Irvine, 2003; Dyer et al., 2002; Dyer et al., 2004; Dyer et al., 2005; Dyer et al., 2008; Dyer et al., 2009). Yet, it seems that fewer studies attending to the couples' joint experience of fertility treatment have been carried out in sub-Saharan Africa (Botha, 1985; Gravett, 2008; Sundby, Mboge, & Sonko, 1998). South African literature solely focused on couple's experiences of infertility treatment is scant and dated, with many acknowledging infertility as a couple issue, but focusing on either the female or male partner. The research projects conducted in the 1980's sampled a very small segment of the population, which makes it limited (Botha, 1985; Van Breda, 1989). Furthermore, the aforementioned research was largely quantitative in nature, and therefore confined to the limits of quantitative measurement when attempting to capture the couple's experience of infertility treatment. Botha (1985) conducted research on South African married couples' experience of infertility in general. This research was conducted from a psychodynamic perspective some 31 years ago. Mabasa (2003) conducted research on the psychological impact of infertility on African women and their extended families. This study gave rise to and indeed acknowledged the idea that there is more than one person who is impacted by the diagnosis of infertility and its treatment. Another SA study conducted by Gravett (2009) in the field of Practical Theology, focused on couples who have been affected by infertility and noted the experiences of couples who have experienced parenthood using varying fertility options. Research conducted by Mabasa (2003) and Gravett (2009) attempted to bridge the aforementioned gaps by exploring African women's experience of infertility and the impact of their involuntary childlessness on the extended family. This can be seen as a positive move regarding gaining unique insights into the South African experience of infertility. However, this research focused on infertility experience in a broad sense and not necessarily the experience of infertility treatment, and negated other cultural experiences of infertility and the treatment process.

South African men's reproductive health knowledge, treatment-seeking behaviour and their experiences of couple infertility have been explored (Dyer et al., 2004). They found that men had little knowledge of the physiology of fertility, the causes of unsuccessful conception and treatment options available. However, male-factor infertility awareness was high. Men seemed involved in treatment seeking and reported experiencing stigmatisation, verbal abuse and loss of social status. What seemed most evident was a call for effective integration of men in infertility management and for providing the option for men to access counselling and



education of the community (Dyer et al., 2004). South African women, on the other hand, seem to experience high levels of psychological distress, with infertile women in abusive relationships at higher risk of experiencing increased abuse from their partner (Dyer et al., 2005). The authors state that effective interventions will be those that implement a bio-psychosocial strategy.

Although research investigating South African couples' responses to infertility has been initiated, they do not seem to examine treatment experiences per se. Dyer, Mokoena, Maritz, and Van der Spuy (2008) conducted a study of couples receiving fertility treatment, but focused on men and women's desire for children, and found that the intensity for parenthood motives reflected the value of children held in the community and therefore has social implications for the involuntarily childless couple. This further substantiates the rationale for encouraging future research which seeks to understand the treatment experiences of the infertile couple accessing treatment in the public health sector.

Critique

Covington and Burns (2006) levelled criticism of earlier literary contributions, citing that they were largely based on theoretical speculations and anecdotal information, which, according to them, meant that they lacked scientific rigour. They go on to state that research which focused on psychological distress relied on researcher designed instruments, lacked control or comparison groups, and sampled small numbers of individuals, which may have compromised the reliability of the outcomes. While the authors recognise the colossal research developments and advancements in reproductive medicine, they vehemently maintain that the psychosocial literature has dawdled in comparison, albeit improvements have been seen in both the quality and quantity of studies in recent decades (Burns & Covington, 1999). It seems that the aforementioned critique provides food for the researcher's thoughts, offering impetus for continued investigation into the experience of infertility. It does, however, seem to cast a bleak shadow on the existing literature. How I have assimilated the criticism is by viewing it as presenting a paradigmatic lens which seems rooted in a quantitative tradition, and may not have the same weight for the researcher working from qualitative methodological perspective. That being said, support for continued research into the psychological experience of infertility is mutually agreed upon by researchers, even if it means our methods and foci differ (Cousineau & Domar, 2007; Covington & Burns, 2006; Domar, Zuttermeister, & Friedman, 1993; Greil, 1997).



Research on the psychological aspects of infertility experience has been hindered for several reasons. Firstly, infertility has traditionally been viewed as a medical condition, rather than also a social problem calling for continued psychological research. Secondly, infertility has been considered taboo in many communities, very pronounced in the African continent where growing the family unit is praised and revered (Hlatshwayo, 2004), and therefore, is not a subject that is easily talked about even under research conditions. Thirdly, infertility is an issue which has seen an increase in Western societies during a time where beliefs about parenthood, roles and importance of having children, has seen a shift. Lastly, research has focused less on infertility experience for individuals and couples, and more on the psychosocial responses to treatment (Inhorn, 2002; Van Balen & Inhorn, 2002). Psychological research on infertility experience has seemed to have taken a shift from research that historically focused solely on individual psychopathology, to the more recent contribution which demonstrates an integrated and interactive view of infertility. The impact of advancing ART has also become a focal area for research (Covington & Burns, 2006). With this, there is a noticeable shift from narrowly focusing on the individual, to researching couples and families. Investigations into responses to assisted reproduction have involved researching individual and couple responses to treatment, as well as the medical outcomes of undergoing treatment. The shifts in research focal areas has attracted other social sciences, and brought with it, a variety of investigative approaches and subsequent methodologies. This can be seen in ethnographic studies (typically used by anthropologists), which tend to focus on reproductive life histories of individuals (Inhorn, 2002; Sundby, 2002). Further contributions include those utilising grounded theory methodologies (Roudsari, Khadivzadeh, & Bahram, 2013; Ticinelli, 2012) and discourse analysis (Fisher & Hammarberg, 2012; Kantor, 2006), which represent only a small fraction of the vast research approaches which have provided additional insights into the experience and impact of infertility. I believe that the more interdisciplinary research is conducted, the more psychologists, working within the field of reproductive health, will be in a position to identify key therapeutic areas, and to deliver the most beneficial therapeutic treatment to individuals and couples (Gannon, Glover, & Abel, 2004; Kirkman, 2001; Olshansky, 1987; Pashigian, 2002; Riessman, 2002; Sundby, 2002).

Whilst Covington and Burns (2006), share an optimistic view of the development of social science research in the field of involuntary childlessness, they do identify remaining gaps in the literature. The salient concerns levelled have been that research has primarily centred on the experiences of white, educated, heterosexual women residing in developed countries. There



have been fewer contributions focusing on the experience of culturally diverse men and women from resource constrained communities, who reside in developing countries with limited access to treatment (Greil, 1997). Furthermore, little focus has been placed on the provision of mental health services in the developing world and therefore leads to inconsistent standards in the provision and utilisation of psychotherapeutic support services as an adjunct to infertility treatment. This research project attempts to address this critique by providing psychological insights into South African couples' experiences of infertility treatment in a public health fertility clinic. Couples utilising the SBAH, primarily come from resource constrained communities, are from various cultural and educational backgrounds, and have divergent infertility histories which have led to their referral to the clinic. I believe this project is a step in the right direction to begin to illuminate couples' experiences of fertility treatment in a developing country, such as SA.

The Void

International studies with a core focus on couples' fertility treatment experiences, utilising an IPA approach, have been conducted mostly in developed European countries. Such examples of research come from the UK (Phillips, Elander, & Montague, 2014) and Belgium (Provoost et al., 2009). In Phillips, Elander, and Montague's (2014) study, they found that the desire for and importance of biological parenthood varied between participants who balanced their fertility goals with maintaining emotional well-being, avoidance of financial difficulties and maintaining a healthy marital relationship. Provoost et al. (2009) investigated how patients speak of their embryos, and how these narratives are related to their decision-making in cases where there are surplus embryos. This study reported that considerations were made based on the genetic link of the embryo to the couple, which elicited hesitance to donate embryos, and secondly, the donation of embryos for research or the decision to discard were evaluated against the value the couple attached to the embryo in light of their confidence in medical science. The research findings conveyed the experiences of couples living in developed countries, however, and did not provide insight into the experiences of those couples in developing countries, like SA. In my examination of the South African literature, research on couples' experiences of infertility treatment from an IPA perspective has not yet been initiated. This project will, therefore, be the first one conducted in SA from an IPA approach, with a key focus on couples' experiences of fertility treatment in the public health sector.



Sociological System

What do different communities say about reproductive health and illness? Do community opinions on reproductive health differ across genders? Are public views on reproductive health pervasive across communities or are there differences in societal opinions? These are only some of the types of questions that medical sociologists seek to understand and explore.

Medical sociologists seem to share a collaborative view of *health* and *illness*. There is a move from viewing health and illness as quantifiable, objective conditions as depicted in the biomedical literature, to recognising them as socially negotiated categories that tell us about a person's wellbeing (Greil, Slauson-Blevins, & McQuillan, 2010). Sociocultural contexts provide the platform for negotiating our taken-for-granted understanding of what it means to be healthy, and conversely, what it means to be ill. Through processes of social definition, professionals, community members and individuals fashion how "sufferers" view themselves and how they would be viewed and treated by others. Greil, Slauson-Blevins, and McQuillan (2010) consider the social construction of infertility in the light of medicalised healthcare. The term "medicalisation" refers to the process by which certain behaviour is understood as a question of health and illness, subject to the opinion of medical authorities (Conrad & Schneider, 1980). Within the biomedical context, infertility is defined as an inability to conceive after 12 months of regular unprotected sexual intercourse (Zegers-Hochschild et al., However, this is only one voice informing our understanding of involuntary 2009). childlessness. How do individuals and couples define infertility? Would a couple be considered "infertile" if they have had unprotected intercourse for 12 months or more but have not embraced a parenthood role? The biomedical definition of infertility explicates a narrow view of infertility and seems to provide a linear understanding of involuntary childlessness: you are either infertile or not, as determined by a medical health specialist.

What it means to be infertile and the social contexts that infuse our understanding of infertility experience, go beyond a single medicalised context. An individuals' ability to have children is socially negotiated as problematic and unless couples embrace parenthood as a desired social role, they do not view themselves as infertile, or seek treatment. Secondly, the biomedical model views infertility as affecting the individual, whereas sociologists view it as a condition that affects a couple, regardless of the one with functional impairment. It is argued that infertility is not only negotiated between the patient and the doctor, but also within the



couple system and in some instances, within social networks. Thirdly, infertility is signalled by the absence of pregnancy and not the presence of symptoms. Infertility is, therefore, the absence of having the desired parenthood role realised. Fourthly, in the case of infertility, as compared to other medical conditions, a multitude of options and possibilities exist rather than focusing on a "cure" (Greil, Slauson-Blevins, & McQuillan, 2010). Alternatives to treatment seeking may be initiated by those who have not conceived a child, such as redefining one's self as "voluntarily childless" or perhaps adopting or fostering a child (Shaw, 2011). Thus, the definition, experience, consequence and management of involuntary childlessness may, for some, not require biomedical intervention, but an alteration of social relationships in some instances or seeking the guidance and/or help from other institutions, such as those offered by different spiritual communities.

I now turn to literature on the experience of infertility, before highlighting research on fertility treatment experience, being the core focus.

A Tale of Two Worlds: Infertility Experiences Across Borders

It comes as no surprise that themes represented in the literature echo the research trends in the field of infertility experience. Polarities in reporting on the experience of infertility and fertility treatment experience are evident across societies, cultures and genders. More specifically, marked differences are noted between developed and developing countries experiences (Greil, Slauson-Blevins, & McQuillan, 2009). In the context of this research project, the salient narratives represented in current literature regarding the experience of involuntary childlessness and treatment experiences, are best understood by employing the bifocal lenses of what Greil, Slauson-Blevins and McQuillan (2009, p.146), call the "two worlds of infertility". The *two worlds* represent differences between infertility experiences in developed countries on the one hand, and developing society's experiences on the other. I employ the metaphor of the "two worlds" to discuss the dominant themes in the literature before moving on to a discussion on the gender differences in experiences of infertility and treatment, and conclude the discussion with research dedicated to couple's experiences of involuntary childlessness and fertility treatment.

Pronatalism. A sociocultural characteristic that plays out quite differently in different parts of the world, influencing how infertility is experienced, is pronatalism (Barden-O'Fallon, 2005; Feldman-Savelsberg, 2002; Hollos, 2003; Parry, 2005; Pashigian, 2002; Pearce, 1999;



Remennick, 2010; Sundby, 2002; Sundby & Jacobus, 2001). Developing countries views of involuntary childlessness tend to differ from those in developed countries. While it can be argued that perhaps every society is pronatalist to some extent, the role, status, and identity of a woman is strongly linked with motherhood more so in some societies than in others. In developed countries, it may be presumed that women who have no children are voluntarily child-free and of those who chose to be childless, it may be viewed as practical and reasonable (Greil, Slauson-Blevins, & McQuillan, 2009). This in stark contrast to developing countries where, for example, Northern Vietnamese women who attempt to conceive, are seen as endeavouring to engage in a normative social role, where womanhood and motherhood are deeply connected concepts (Pashigan, 2002). Remennick's (2010) interview of a small sample of Israeli women revealed strong pronatalist views, where women did not believe that voluntary childlessness is an option. Israel's pronatalist views are strongly echoed in the state's subsidisation of IVF and surrogacy (Birenbaum-Carmeli, 2004). In developing societies, women's identities, acceptance in the community, and achievement of adult status are often linked with having children (Barden-O'Fallon, 2005; Hollos, 2003; Riessman, 2002). For women in Cameroon for example, infertility can be viewed as a source of poverty (Feldman-Savelsberg, 2002). In Kerala, India, having children is associated with women's wellbeing and authority (Riessman, 2002). According to Sundby and Jacobus (2001) in parts of southern Africa, bearing children entitles women to share in their husband's material goods. Thus, in many developing countries, womanhood, status and wealth are wrapped up in the women's ability to reproduce. In countries where there is no concept of choosing the status of being "voluntarily childless", infertility becomes impossible to hide, with stigma and distress often the result in developing societies (Dyer et al., 2005).

In sub-Sahara Africa, involuntary childlessness is generally overlooked as a public health issue, despite African countries being generally pronatalist (Van der Spuy, 2009). Perhaps there are many reasons for this, one being that for policymakers, overpopulation is more of a concern than infertility is (Bos, Van Balen, & Visser, 2005). Africa has the highest global incidence of infertility, which is contrasted by the low incidence of *voluntary* childlessness (Bambra, 1999; Dyer et al., 2008; Ombelet & Campo, 2007). The irony here is two-fold: the majority of couples confronted with infertility reside in developing countries, where a) there is a lack of adequate general healthcare facilities, and b) the low incidence of voluntary childlessness is set against the backdrop of pronatalist ideology where fertility treatment is a taboo subject in many African cultures, met with scorn and prejudice (Dyer et al.,



2008; Ombelet & Campo, 2007; Ombelet et al., 2008). The plight of an African couple from a resource poor community may be one where access to good reproductive health facilities may be financially difficult (not only for the couple, but for the state to provide the facilities in the first place) and secondly, may be met with prejudice from the community, where a culture of silence around fertility difficulties is often the case (Ombelet & Campo, 2007). The impact and resultant implications of this contradiction are far reaching, with cultural, individual, economic and social contexts being affected (Hammarberg & Kirkman, 2013; Ombelet & Campo, 2007).

Economy. One of the obvious differences between the *two worlds* is economic disparities, which impacts fertility treatment infrastructure; the provision of affordable treatment options; and reproductive education programs available to the general population(Daar & Merali, 2002; Luna, 2002; Robert & Nachtigall, 2006; Sharma, Mittal, & Aggarwal, 2009; Tangwa, 2002). In a developing country, this inherently boils down to whether a couple will have access to good quality fertility treatment if needed and whether this treatment is affordable and accessible. This picture may be very different from the treatment experiences of couples that reside in developed countries, where their treatment experience narratives may talk to financial concerns around affordability, but they do not inherently face the reality of an impoverished community faced with basic bread and butter issues. In general, the developed world literature treats infertility as a medical, ethical and psychological issue, whereas research on developing countries attends to the sociocultural context of infertility (Bos, Van Balen, & Visser, 2005).

Fortunately, the WHO has drawn attention to encouraging continued developments in affordable ART in developing countries, with parallel attention given to social and ethical implications in developing countries (Daar & Merali, 2002; Luna, 2002; Pennings & Ombelet, 2007; Tangwa, 2002). The treatment experience for couples who live in resource-poor conditions may be quite different from those who live in developed countries, which may be experienced differently from those in a position to design and implement policies in addressing infertility (Bos, Van Balen, & Visser, 2005; Nachtigall, 2006).

Gatekeepers. How policymakers view infertility in developing countries, may be very different from the views of those who experience infertility. Whilst policy in developing countries usually centres more on addressing the problem of overpopulation those policies do not address the problem of infertility. The viewpoint of those experiencing infertility is often



different from the views and focus of the policy makers (Bos, Van Balen, & Gerrits, 2001; Nachtigall, 2006; Visser, 2005). The availability of reproductive technology can play a role in shaping the social perceptions of infertility and societal and individual responses to it (Kirkman & Rosenthal, 1999). Prior to the advent of ART, childlessness may have been more socially acceptable (Letherby, 2002). Today, it may be argued that if a couple cannot conceive a child, fostering is an option. This is evident in Gambia, where a strong fostering tradition exists in the midst of stigmatisation of infertility (Sundby, 1997). However, alternatives to producing your own offspring, are not always indicated, and therefore, fertility treatment offered in countries, are regulated by laws within those countries.

In a developing country such as SA, poverty, inequality and ever growing unmet needs, complicate the attainment of rights. The South African Constitution states that every South African citizen has the right to have access to (a) healthcare services, including reproductive healthcare (SA Constitution, Section 27). Excellent legislation that finds itself in the midst of a cesspool of socioeconomic realities, provides at best, a context in which the progressive realisation of Constitutional rights is strived for (Heywood, 2009). The South African healthcare system is directed towards addressing health problems such as infectious disease management. Infertility, on the other hand, is a non-life-threatening condition, and as such, is largely neglected by policy makers (Teoh & Maheshwari, 2014). When it comes to reproductive health, the focus is largely on family planning and education programs targeting prevention of pregnancy (Dyer et al., 2008; Huyser & Boyd, 2013; Ombelet & Campo, 2007).

Public funded fertility treatment has its own set of challenges: Firstly, it is rarely readily available; Secondly, waiting lists for treatment can be as long as years; Thirdly, treatment costs present as mostly unaffordable for the majority of the low-income earners (Huyser & Fourie, 2010; Teoh & Maheshwari, 2014). The conditions of the country impact not only its people, but also public and tertiary ART units, as well as private practices in so far as their ability to adequately provide reproductive health screening and fertility treatment possibilities (Huyser & Boyd, 2013). The running costs of an ART programme can be very high. Therefore, the issue of gatekeeping, in my opinion, is not only legitimised in legislation, but can be mediated by the socioeconomic factors of the country, as can be seen in the South African context.

Patriarchy. Patriarchy may shape the experience of infertility, and with that, how it is expressed and managed. Depending on the degree of patriarchy, how it is exercised and how



it impacts the importance placed on the motherhood role, as well as the varying roles available to women other than motherhood, varies from one society to the next (Greil, Slauson-Blevins, & McQuillan, 2010). In contexts where motherhood is so intrinsically connected to a woman's identity and self-worth, the suffering of the infertile woman is usually intensified and can lead to marriage difficulties, domestic violence, stigmatisation and in some cases, ostracism (Fathalla, 2001). In Egypt for example, even in instances where the male partner is the identified patient, women in many instances bear the burden of infertility (Inhorn, 2003). This is not unique to Northern African countries, but is seen in Bangladesh where the treatment prescribed for infertility is often *remarriage* for the male partner (Nahar, 2007). In SA, women often bear the burden of infertility, facing societal stigmatisation (Ombelet & Campo, 2007).

Although patriarchy may be more diluted in developed societies, it is not irrelevant to the experience of infertility in them. Throsby and Gill's (2004) qualitative study of men residing in the UK who discontinued IVF treatment revealed that they experienced infertility as emasculating. While their wives received empathy, they were teased, resulting in men shifting the blame to their partner. Gough (2016) claims that we can get vivid insights into men's help seeking tendencies, how they express their experiences and how they manage their masculine identities, by exploring online spaces, for example. Online platforms symbolised a safe space for these men, where they felt a sense of support and connectedness as peers (Colineau & Paris, 2010). Furthermore, forums provided a place for mental health support to ethnic minority men, who would otherwise not have sought help in traditional contexts due to mistrust of traditional supportive services (Watkins & Jefferson, 2013).

Broadly speaking, men have reportedly experienced a poorer perception of psychosocial support, when compared to their partner's experience of support and tend to feel largely excluded from the fertility process due to their partner being isolated as the primary fertility candidate (Agostini et al., 2011; Schmidt, 2009). Men in some instances experience infertility related stigma, which may lead to men feeling emasculated personally and socially as a result (Barnes, 2014; Connell, 1995). Emotional reactions of men to their childlessness have centred on how it poses a threat to marital stability; loss of social status, and stigmatisation (Dyer et al., 2004). A quantitative study of Iranian men with male-factor infertility showed higher depression scores with a tendency towards anxiety (Baluch, Nasseri, & Aghssa, 1998). This concurs with a study of Zimbabwean men who showed that one-third presented with signs of



depression (Folkvord, Odegaard, & Sundby, 2005). What does the literature say about women's experience of infertility?

Many studies support the notion that women experience high stress levels. Women experiencing conception difficulties display depression and anxiety. Studies that look at the gender differences in fertility-specific distress, have shown that women tend to experience more infertility-related distress than men (Anderson, Sharp, Rattray, & Irvine, 2003; Eugster & Vingerhoets, 1999; Henning, Strauss, &Strauss, 2002; Holter, Anderheim, Bergh, & Moller, 2006; Savitz-Smith, 2003). Relinquishing the intention to have a child has been one of the factors associated with the distress for women in particular (Brothers & Maddux, 2003; White & McQuillan, 2006). Women tend to experience higher levels of stigma than men (Slade, O'Neil, Simpson, & Lashen, 2007) and tend to experience changes in mood, jealousy of those who have actualised their parenthood role and a sense of time urgency (Hjelmstedt et al., 1999).

In many instances, childlessness can lead to social isolation and prejudice, domestic violence and neglect, and has great financial impact, to name but a few sequelae (Ombelet & Campo, 2007). The salient narratives represented in current literature regarding the experience of involuntary childlessness, is that it can create dissonance on personal, societal and spiritual levels (Anderson, Sharp, Rattray, & Irvine, 2003; Eugster & Vingerhoets, 1999; Henning, Strauss, & Strauss, 2002; Holter, Anderheim, Bergh, & Moller, 2006; Savitz-Smith, 2003). It can lead to social and psychological suffering, which can place significant pressure on the couple system (Fathalla, 2001).

The preceding discussion highlights the "stratification of infertility", which refers to how fertility experience is affected by economic, social and public health issues. The preponderance of poverty, malnutrition, lifestyle choices, STI's that affect fertility and possibly general health, lack of reproductive knowledge and fertility preservation; lack of availability or access to good quality medical treatment and with that, an inability to access medical treatments based on cultural, religious, ethical, or legislative reasons, make for a complex picture when considering fertility treatment experience. Infertility is not only a medical condition, but is a social, emotional, and spiritual experience, as is the treatment of involuntary childlessness (Burns & Covington, 1999).



Fertility Treatment Experiences

Running parallel to the broad literature on the experience of infertility, are research contributions focusing more closely on fertility *treatment* experience. Research has been conducted in developed countries as well as developing countries on the topic of treatment experience, examining, for example, factors influencing the experience of infertility treatment; access to treatment; the availability and acceptance of the use of alternative care systems in treating infertility; factors that influence treatment seeking; couples experiences of treatment and the psychological and physical experience of fertility treatment, have all been areas of interest (Becker, Castrillo, Jackson, & Nachtigall, 2005; Beckman & Harvey, 2005; Bitler & Schmidt, 2006; Culley & Hudson, 2007; Dyer et al., 2002; Henne & Bundorf, 2008; Inhorn & Fakih, 2005; Jain, 2006; Ombelet et al., 2008; Sundby, 1997; Sundby, 2002; Sundby & Jacobs, 2001; Sundby, Mboge, & Sonko, 1998; Tain, 2003; Van Balen & Gerrits, 2001; White, McQuillan, & Greil, 2006). I begin the discussion with examining the factors and impact of those factors on access to care in both developed and developing countries, which is an issue deeply connected to this research project.

Factors mediating access and provision of care. One would think access to care would be a concern unique to developing countries. Not so. Access to fertility treatment is far more complex than a discussion that attends only to financial viability. Undoubtedly finances do have a profound impact on the provision of services to its people, and with that, the ability for people in resource-poor communities to access such treatments. In both developed and developing countries several factors may mediate access, for example, the State's support of treatment and the consequent facilities made available to the general public, as well as the strength and importance religion plays in society and how that may influence the provision of medical treatment that is considered as being acceptable (Greil et al., 2010).

The underrepresentation of minorities. Cultural minorities in the UK, the Netherlands, and the USA for example, have less access to treatment than White people (Becker, Castrillo, Jackson, & Nachtigall, 2005; Beckman & Harvey, 2005; Bitler & Schmidt, 2006; Culley & Hudson, 2007; Henne & Bundorf, 2008; Inhorn & Fakih, 2005; Jain, 2006; White, McQuillan, & Greil, 2006). Jain's (2006) study of fertility treatment-seeking trends in the state of Massachusetts in the USA, found that Latino women, poor women and poorly educated women are underrepresented in ART clinics. Further supporting the notion that minorities in America are not accessing fertility treatment as much as other cultural groups, are studies such as those



conducted by Feinberg, Larsen, Catherino, Zhang, and Armstrong (2006) and Feinberg, Larsen, Wah, Alvero, and Armstrong (2007), who found that Hispanics were underrepresented on a military fertility clinic, even though everyone was guaranteed access to treatment. Despite ART being subsidised by the state in France, Tain's (2003) research showed that socioeconomic status and occupation do not affect the utilisation of ART, in fact, the research showed that low socioeconomic status French women make up the majority of early treatment seekers when compared to other economic groups. Patterns in usage and the experience of infertility may change as new treatments become available, where it can be argued that due to the increase in marketing of reproductive technologies, couples are seeking help much earlier than they did before, which may, in some instances, lead to unnecessary treatments (Mitchell, 2002).

The plight of the poor. Access to fertility treatment in developing countries is arguably more limited, in comparison to developed countries for obvious reasons (Nachtigall, 2005; Ombelet et al., 2008; Van Balen & Gerrits, 2001). Most couples confronted with infertility reside in developing countries, where there is a lack of adequate general healthcare (Dyer et al., 2008; Ombelet & Campo, 2007; Ombelet et al., 2008). Couples attempting to access fertility treatment in resource-constrained communities are often faced with a healthcare system that is challenged by financial constraints, limited budgets and infrastructure issues (Robert & Nachtigall, 2006; Sharma, Mittal, & Aggarwal, 2009). In resource-poor countries, reproductive health treatment is synonymous with the prevention of pregnancy, with little attention being paid to infertility diagnosis and treatment (Ombelet & Campo, 2007). Estimates on the pervasiveness of involuntary childlessness and analysis of demographic data in poor countries can be flawed as it is reliant on advanced healthcare systems and infertility studies often extrapolate fertility data to make inferences on infertility rates, which can underestimate the prevalence (Sharma, Mittal, & Aggarwal, 2009). Also, we have the issue of generating data from treatment seekers (for example, for clinic records of clinic-based patients), and therefore, do not have a clear picture that is inclusive of those who do not seek treatment but who face childlessness.

Southern African countries, such as Botswana, Zimbabwe and Lesotho report a prevalence of between 15-22%, which is much higher than rates of 8-13% found in most other Eastern African countries (Sharma, Mittal, & Aggarwal, 2009). Fertility treatment centres in Gambia and Zimbabwe are faced with a situation where the demand surpasses the centre's capacity to provide good quality services. Reports of high hospital admissions, coupled with



inappropriate healthcare and lack of networking between healthcare professionals means that people may experience the same treatment several times (Sundby, 1997; Sundby, 2002; Sundby & Jacobs, 2001; Sundby, Mboge & Sonko, 1998). Indian, Egyptian, and Gambian women who are able to afford fertility treatment have access to advanced treatment facilities; in stark contrast to poor and middle-class women whose needs are often not met (Sundby, 2002; Sundby, Mboge& Sonko, 1998). SA is no exception, with one-quarter of female clinic patients having sought care for over five years before receiving their first appointment at an infertility clinic (Dyer et al., 2002).

An assumption often made is that infertility does not present as a "problem" in resourceconstrained communities, where fertility rates are high. This assumption is challenged by research which demonstrates that the reality and consequence for women, who experience involuntary childlessness in low-income countries, can be dire. In Africa, women are frequently stigmatised, ostracised, isolated and neglected by their family and their community for failure to achieve pregnancy (Hammarberg & Kirkman, 2013). The irony is that in some cases, certain socio-cultural practices may be directly linked as a causal factor for a woman experiencing infertility. In Africa, women may be inclined to consult traditional healers, in an attempt to understand the aetiology of their childlessness, and to receive treatment. According to a study undertaken by Dyer et al. (2002), women who consulted traditional healers received "herbs" or "medicine" to drink in order to be "cleaned". Some women were told that their infertility was due to a bewitchment by a jealous woman. Some women are considered possessed by ancestors and others feared that witchcraft prevented doctors from identifying the cause of their childlessness.

Low literacy rates, a consequence of poor education in Africa, have been cited as creating barriers to women accessing information regarding reproductive health and disease. Information is imperative as it is the basis for prevention and treatment. Healthcare workers also need to be acutely aware of the context in which they operate. Careful consideration should be paid to the personal experiences of their patients in light of cultural views held in the community regarding childlessness. Furthermore, healthcare workers should be mindful of the level of education of their patients, so that information delivery is given in a manner that is understood by the patient, so that clinic attendance is not deterred (Dyer et al., 2002; Ndowa, Lusti-Narasimhan, & Unemo, 2012; Van der Spuy, 2009).



As can be seen, infertility is a multidimensional problem in resource-poor countries, where women, in many instances, assume the burden of this individual, social, medical and economic problem. There is a move in the field of reproductive health, to prevent infection, especially in low resource communities. There is further evidence for lobbying for healthcare facilities that are both accessible and affordable. This calls for governments to treat infertility and its prevention, with the importance it deserves (Hammarberg & Kirkman, 2013; Ombelet & Campo, 2007; Sharma et al., 2009; Van der Spuy, 2009).

Increasing access to care, by attempting to provide more affordable fertility treatment solutions coupled with increasing coverage, is important, especially in economically poor environments (Hammarberg & Kirkman, 2013; Ombelet & Campo, 2007; Sharma et al., 2009; Van der Spuy, 2009). However, reducing costs and increasing coverage alone, does not necessarily equate to an increase in help-seeking, for example. The interconnectedness between religious behaviours, beliefs and help-seeking calls for deeper understanding, as the meanings of symptoms and outcomes are critical to understanding the provision and accessibility of medical care (Greil et al., 2010).

Cultural practices. The pursuit for a child, whether biologically, socially or psychologically motivated, has lead men and women to seek help, and in some instances, to go to extreme measures. According to Burns and Covington (2000), all cultures consider involuntary childlessness as a crisis. As such, every society has culturally approved solutions which involve either an individual or the couple, or solutions which alter social relationships (for example, adoption, fostering, divorce), lean on spiritual intercession (e.g. through prayer or pilgrimage) or medicinal treatment (e.g. consulting a traditional healer or herbalist). Developed societies, such as China, for example, place strong ideological importance on birthing sons. This, in turn, has had a significant impact on the utilisation of ART in China (Handwerker, 2002). Whereas, couples in developed communities may be more inclined to present medical treatment first, couples from developing communities may utilise alternative medicinal remedies, such as taking herbs or meeting with traditional healers (Burns & Covington, 1999; Ombelet & Campo, 2007; Ombelet et al., 2008).

Each community is regulated by norms and customs that are practised and therefore influence attitudes and behaviours of people living in communities, where traditional and cultural practices are noticeable demonstrations of beliefs in practice. Some traditional



practices continue and become deeply embedded in certain societies. Alternative methods that have been accessed by couples in attempting to treat infertility are methods such as acupuncture and reiki (Coulson & Jenkins, 2005; Pei et al., 2005) and are often used in conjunction with Western medicine (Burns & Convington, 2000).

As discussed under the preventable causes of infertility in Chapter 2, page 39 (under the sub-heading: Socio-cultural factors) there are numerous reasons for why harmful traditional practices prevail: poverty; poor access to education; and the continued reverence of a patriarchal system. Females are at particular risk for harmful traditional practices, where in some instances, these violate the integrity of women and female children, such as in the case of Female Genital Mutilation (FGM) which is performed in certain parts of Africa and the Middle East (Moges, 2003).

Societies that are pronatalistic, may promote certain treatments which are not medically proven and which may result in damage to the reproductive system. Socio-cultural practices such as FGM, symbolising a condition for marriage in some communities. In some communities, men pay the parents of the bride, which is dependent on the woman fulfilling traditional norms. FGM is a religious requirement in some societies and may also symbolise the commitment of a community to continuing tradition (Moges, 2003). FGM is often performed by midwives who have limited knowledge of anatomy, leading to haemorrhage, sepsis, obstructed labour and infertility in many cases (Hammarberg & Kirkman, 2013; Sharma et al., 2009). In resource-poor communities, where availability of and access to healthcare facilities can be challenging, this can negatively impact fecundity.

Not all traditional cultural practices are harmful, and may provide alternative care solutions. Developing societies seem to be more open to the idea of treating infertility through accessing alternative care systems prior to seeking clinic based assistance (Kielman, 1998). There seems to be greater acceptance and availability of alternative care systems in developing societies. Clinic-based studies in SA (Dyer et al., 2004) as well as Zimbabwe (Folkvord, Odegaard, & Sudby, 2005) for example, have shown that patients had first consulted with traditional healers prior to pursuing a western medicine route. The most common treatment for women in the Bangladeshi slums, for example, involves the use of herbalists and healers, whilst the treatment for men, on the other hand, is often remarriage (Nahar et al., 2000).



A South African study conducted at the Groote Schuur Hospital Infertility Clinic in Cape Town, found that many black women consulted with traditional healers in an attempt to treat their infertility. Women who sought the help of a traditional healer received "herbs" or "medicine" to drink with the view of being cleansed. Others were told by witch doctors that they had been bewitched, which was preventing pregnancy as well as preventing medical treatment from succeeding. Others were told they had been possessed by ancestors and the cure for infertility and possession was to take up the role of a traditional healer (Dyer et al., 2002). These studies demonstrate how cultural practices can inform how infertility is conceptualised and treated.

Factors influencing treatment seeking. The conundrum inherent in treatment seeking behaviours is much like that presented by the "chicken and egg" scenario: which one came first? Does self-definition of infertility lead to treatment seeking, or, does this deter patients from seeking treatment? There are conflicting narratives. On the one hand, Greil and McQuillan (2004) and later, White and McQuillan (2006), supports the notion that defining one's self as infertile, is the core of what leads to treatment seeking, whilst Bunting and Boivin (2007) found that women were less likely to seek treatment when concerned about being identified as infertile. Nevertheless, treatment-seeking does not rest on the definition of unintended childlessness alone. Other factors seem to have bearing on initiating treatment, such as gender (Greil, 1991).

It seems that women tend to be more inclined to initiate treatment (Daniluk, 2001; Throsby & Grill, 2004) than men. Although this seems to be the trend, incongruously women seem to experience treatment as intensely stressful, unpleasant and emotionally taxing (Peddie, Van Teijlingen, & Bhattacharya, 2005; Yebei, 2000), whilst men also tend to experience stress and anxiety, their stress seems to be mitigated by supportive medical staff in the treatment process (Brucker & McKenry, 2004; Schmidt et al., 2003; Schneider & Forthofer, 2005). Broadly speaking, when taking a close look at literature attending to long-term treatment experiences, the focus is largely on the female partner experience of treatment than on male or couple experiences (Greil, Slauson-Blevins, & McQuillan, 2009). Even after a long period of time has lapsed after receiving treatment, women who have experienced fertility treatment over a lengthily period, describe it as representing a difficult time in their lives. With the absence of successful pregnancy, women tend to feel a sense of failure and a sense of uncertainty (Sundby et al., 2007; Zucker, 1999). Infertility experience is contextual. It can be understood as not only



representing a medical condition, but also a psychological and social one. Emphasis has shifted from coping with childlessness through engaging in alternative social roles, such as helping in the rearing of the children of others, to active engagement in medical interventions, even in the most difficult of circumstances.

Even though infertility is not solely a medical condition, the biomedical context can have a profound impact on how individuals experience and access treatment. According to Burns and Covington (2000), the "medicalisation of infertility" has lead people to seek medical treatment and to assume the "passive patient role" in the patient-doctor relationship, in the hopes of fulfilling their desired parenthood status. The medicalisation of infertility can be associated with medical jargon and terminology, as well as medical procedures which may be utilised in the treatment of infertility. These very aspects have been shown to deter or intimidate patients, especially in cases where language barriers occur (Ulrich & Weatherall, 2000). Infertility treatment experience has also been described as dominating patients' daily routines (Daniluk, 2001) as there is a *time* dimension that cannot be ignored. From timed-intercourse, to the timing of ovulation, to the length of time examinations and treatment procedures take and the resultant impact these have on time away from work, to taking medication and the time dedicated to thinking about involuntary childlessness as disruption to their daily lives ensues. Time can have a significant impact on patient's ability to engage in and sustain treatment due to the consequent disruption and inconvenience it can create in other facets of their lives (Redshaw, Hockley, & Davidson, 2007) such as being late for work following doctor's appointments and/or other medical procedures, for example (Steuber & Solomon, 2008). Treatment for involuntary childlessness requires that healthcare professionals take into consideration the people being treated and the breadth the impact of treatment can have on patients' and their lives in totality.

When considering treatment experiences, it becomes increasingly clear that there is a difference between treating a disease and treating the person. Research shows that people who seek medical treatment for involuntary childlessness wish to receive comprehensive information regarding their treatment process and care that is patient-centred (Schmidt et al., 2003; Souter, Penney, Hopton, & Templeton, 1998). Treatment has been described in the literature as being experienced as lacking continuity, as inconvenient, and as carrying an emotional and physical price tag (Redshaw, Hockley, & Davidson, 2007). All of which could contribute to reasons why patients decide to discontinue treatment in some instances.



Factors mediating the termination of treatment. Research indicates that patients do not follow through with treatment for many reasons. Despite the cause, it seems that the decision to terminate treatment is not any easy one for women, where men tend to motivate for discontinuing fertility treatment to restore their wives psychological and physical welfare (Greil, 1991; Throsby & Gill, 2004). However, women tend to struggle to stop treatment despite the psychological burden they say it has on them (Olivius, Friden, Borg, & Bergh, 2004). Verhaak et al.'s (2007) study of women, who underwent IVF and stopped treatment, showed that these women reported reduced anxiety and depression symptoms. Terminating treatment can lead to a self-reflective period, followed by acceptance of their infertility (Peddie, Van Teijlingen, & Bhattacharya, 2005). Other studies, on the other hand, show that some women never fully accept their childlessness, until they reach menopause (Johansson & Berg, 2005), while others reframe their idea of family to include adoption and childfree lifestyles (Su & Chen, 2006; Ulrich & Weatherall, 2000). When it comes to couples, they do not seem to regret engaging in the process of IVF, even in the face of it being unsuccessful. Couples seem to view it as their best chance to have conceived (Johansson & Berg, 2005; Throsby & Gill, 2004). Research seems to point to long-term negative consequences of infertility among those who struggle with involuntary childlessness (McQuillan, Greil, White, & Jacob, 2003; McQuillan, Stone, & Greil, 2007). This very statement substantiates the need for this kind of research project, and future studies, so that with additional insights, we can best support couples who actively engage in fertility treatment, as well as to equip healthcare professionals with a breadth of knowledge when treating the person in context.

I turn my attention now to the spiritual narratives, which concludes the literature review on infertility treatment experience.

Spiritual System

As I pause to contemplate the directions the literature has steered me, it has become increasingly clearer that the body of research on infertility experience continues to grow. Research has, and continues to focus on the medical, psychological, and social consequences of infertility, and to a lesser extent, on the religious and spiritual dimensions of infertility (Roudsari, Allan, & Smith, 2007). Engel (1989) and White, Williams, and Greenberg (1996) proposed a bio-psycho-social model for care which recognises the person as a *being-in-relationship*. This can easily extend to encompass the spiritual domain in considering reproductive healthcare. In general, healthcare has increasingly moved towards a more patient-



centred approach, and with that, spirituality has become an important consideration (Stewart et al., 1999). Cognisant that infertility is a multifaceted issue, reproductive healthcare practitioners, in my opinion, are called to consider all aspects of holistic care when beginning to work with individuals and couples with involuntary childlessness. In that vein, holistic care takes into consideration the body and mind, the social context and the spiritual needs of individuals. The broad landscape of infertility requires that one must consider the interplay of relationships in managing infertility: the couple-doctor relationship; the couple-spiritual relationship; the couple-socioeconomic relationship, to name but a few.

Spirituality

Although the definition of *spirituality* varies across the literature, Speck (2004) provides a workable way to view spirituality. He argues that although spirituality can be a rather ambiguous and elusive concept, it is widely accepted that it is related to, but not always one and the same as, religion, which suggests that religion should be positioned within the broader category of spirituality. With that, he acknowledges that there are varying degrees of interrelatedness between religion and spirituality. Current literature concurs, describing spirituality as a dynamic, and intrinsic aspect of humanity, through which people seek meaning, purpose and transcendence, and where people engage in and experience a relationship with self, family, community, society, nature and the sacred (Berry, 2005; Roudsari, Allan, & Smith, 2007). A person's spirituality is expressed through their beliefs and values, traditions, and through participation in practices (Puchalski, Blatt, Kogan, & Butler, 2014). After engaging with the spiritual literature, I acknowledge the breadth, depth and variance in how one can and could view spirituality and the place it holds in infertility experience.

The literature review presented here offers a microcosm of spiritual insights that have bearing on infertility experience, and more specifically, fertility treatment experiences.

Barren

Religion, family and medicine are institutions which promote family formation, each encouraging the actualisation of parenthood differently (Jennings, 2010). Globally, infertility is recognised as a distressing experience that has the potential of threatening individual, marital, family and social stability (Roudsari & Allan, 2011; Taymor & Bresnick, 1979). For the people who struggle with involuntary childlessness, they confront a multi-layered set of biological, psychological, social and spiritual dilemmas (Roudsari & Allan, 2011).



Infertility as a spiritual crisis can present in a multitude of ways. A South African study, for example, conducted by Sewpaul (1999) examining the cultural views held about fertility, and the impact of religion on handling infertility, reflected similarities across different religious and cultural groups. The most pervasive narrative noted in participant responses, across all religious faiths, was that infertility was perceived as *punishment* for wrong-doing. The impact of religion on the experience of infertility seemed to be mediated by the level of involvement participants had with religion, their personal conception of a Being⁵, and their sense of self in relation to a Being. When we consider the spiritual dimensions of a person, we are open to how people may lean on religious and/or spiritual beliefs for support as they cope with crisis, and how they may draw on spiritual beliefs as they attempt to find meaning and hope in their suffering. Spirituality and beliefs have further implication for understanding how the infertile couple may view reproductive technologies and options available to them that may be at odds with their belief systems (Roudsari, Allan, & Smith, 2007). The moral and ethical questions regarding fertility treatment are only a segment of the dilemma couples may be faced with.

A core component of spiritual distress that is reported in the literature is experiencing a sense of loss (Speck, 2004). People have reported feeling a sense of loss of meaning in life. People have shared feeling a sense of inner fragmentation which can lead to alienation from self and others. Furthermore, participants have reported a sense of hopelessness, and have reported feeling like they have experienced the loss of a Being (for those who are religious) (Speck, 2004). Couples may experience feelings of grief and loss, not only of the loss of the parenthood role they had once dreamt of, but also the loss of the idea that the Being answers all prayers and performs miracles. In this respect, infertility also presents as a crisis in faith, where either the individual or couple, may experience periods of doubt, anger, sadness and a need for support (Schlumpf, n.d.). This is reminiscent with the psychological reactions detailed in the psychological grief and bereavement theories, which further substantiates a need for holistic reproductive healthcare with ethical awareness (Burns & Covington, 1999; Kuchenhoff, 1999; Lukse & Vacc, 1999).

Science with a Conscience

Broadly speaking, the sociocultural context shapes fertility treatment infrastructure and the consequent treatment offered to the public. Many studies illustrate the negative impact

⁵ I refer to Being as an inclusive term to include a Deity across all religious boarders.



infertility can have on economic, family, religious and psychological wellbeing (Charlish, & Davies, 2007; Fathalla, 2001). In particular, concerns can arise for couples based on their ideological and religious belief systems (Fathalla, 2001). How do different religious ideologies inform societies' views on infertility and how do they shape infrastructure and access to treatment? Ethical concerns regarding the integrity of medical procedures, such as genetic testing and treatment, are seen as more of a concern in some religions, than in others. Beliefs that specific treatments are unsupported by religious doctrine may, in some instances, lead to treatment refusal (Greil et al., 2010).

The relationship between religion and medical service utilisation is a complex one since religiosity may be associated with beliefs that may promote or hinder medical service utilisation. Greil et al. (2010) argue that although religiosity is not directly associated with accessing fertility treatment, it is indirectly associated by mediating variables that operate in opposing directions. In cases where religiosity is associated with strong importance being placed on motherhood, this may, in turn, increase the likelihood for help-seeking. Religiosity is further associated with ethical concerns about fertility treatment, which may be associated with a decrease in likelihood of help-seeking. The influence of religiosity on fertility treatment help-seeking is, therefore, indirect and complex. Ethical attitudes of patients and reproductive healthcare specialists are influenced by societal beliefs, which reflect the interests of theologians, physicians, policy-makers, sociologists, economists and policy makers (Serour, 2002; Serour, 2005). Policy-makers are guided by international guidelines when faced with making ethical policy decisions that are tailored to their country. Therefore, ethical conduct ultimately rests on searching for values that lead to an ethically informed decision.

The Middle East. Three dominant religions, namely Judaism, Christianity and Islam are represented in the Middle East. There, religion holds a pivotal place and influences behaviours, attitudes, practices, and with that, policy-making. Globally, over the past two decades, religions' influence over behaviours has gradually lost impetus. However, religious beliefs still strongly shape the behaviours of the Middle Eastern people today (Serour, 2002; Serour, 2005). Procreation and the preservation of humankind are important to the Middle Eastern people, and therefore fertility treatment is a sensitive issue as it is evaluated against the backdrop of attitudes and cultural perspectives that may consider certain treatment options, unethical. Women's social status, dignity and self-esteem are closely linked to her ability to



have children, where producing offspring is regarded as a family commitment, and not a mere physiological and social function (Serour, Aboulghar, & Mansour, 1995).

Treatment modalities for infertility, such as hormonal therapy and corrective surgery, for example, may be deemed ethical, so long as the treatment does not separate the bonding of the sexual act from the conception process. With the development of ART, it became possible to separate reproduction from sexual intercourse, which has provoked ethical discussions. ART has made it possible for a third party to be a part of the reproductive process, whether through providing sperm, an egg, an embryo or surrogacy. At present, ART guidelines for Christians and Muslims are almost the same in the Middle East (Serour, 2000; Serour, 2005). For example, there is agreement that semen for the use of AI, if produced by the husband, can be utilised when no other methods result in pregnancy. The aforementioned examples represent just a few spiritual considerations that influence and inform couples views on the various ART available to them, which in turn inform how the patient-doctor relationship will treat the conception difficulties of the couple.

India. Another example of how religious and medical institutions have an impact on fertility treatment considerations is exemplified by how treatment in India is shaped by Indian ideology that centres on the purity of marriage and family, where adoption is not considered an option. According to Islamic beliefs, adoption and donor insemination is prohibited, where religious leaders consider these alternative solutions as unacceptable because, in the use of either of these methods, there are no blood ties to the father and no maternal bond between mother and child (Folkvord, Odegaard, & Sudby, 2005;Inhorn, 2000; Schenker, 1992; Schenker, 1997). In the Islamic faith, concerns have centred on the purity of the family's genetic ancestry when fertility treatment is utilised (Fathalla, 2001). What would it mean for the doctor-couple relationship when a specific treatment may be indicated but comes up against religious ideology? How is this mediated within the doctor-couple relationship? I believe that this is an important consideration for reproductive specialists to consider. In my humble opinion, an imperative part of the initial consultation with the couple should address their religious background and a frank discussion, insight and understanding should be established from as early on as possible, when a couple presents for treatment, so that both parties are making mutually beneficial, and informed decisions from the outset.



Africa.Studies conducted in Africa demonstrated a spiritual etiological understanding of involuntary childlessness. Supernatural narratives on infertility as being caused by witchcraft, possession, a curse and binding, have been some of the etiological explanations given (Inhorn, 1994; Molock, 1999; Okonofua, 1999). According to Okonofua (1999), Nigerian people attributed infertility to promiscuity and therefore as punishment for their licentious ways. Other studies have indicated that participants reported feeling like they must have done something immoral to deserve childlessness. Wrestling with what they must have done to deserve such punishment (such as have premarital sex), participants seemed to attempt to reconcile the incongruence between expected experience and lived experience (Dyer et al., 2002; Ireland, 1993; Kantor, 2006). The importance of spiritual ideologies regarding procreation is exemplified by a Nigerian practice where women without children who pass away, are buried on the outskirts of town with others who were viewed as outcasts in the community (Okonofua, 1999). This is a stark example of the clash between pronatalist views, religious ideology and societal practices.

Judaism.In the Jewish faith, scriptures direct Jews to procreate. Rabbinic authorities, in accordance with Jewish Law (Halacha), agree that ART is acceptable so long as the eggs and sperm used in treatment, are that of the couple being treated (Wahrman, 2016). Most rabbinical authorities deem donor insemination as an unacceptable treatment option, especially when considering the use of semen of a Jewish donor. When it comes to IVF, many Jewish religious authorities permit the collection of semen through coitus interruptus or collected from a condom utilised during intercourse, as permissible. Egg donation or embryo donation is viewed as separate from the owner of the egg, and the environment in which the embryo is conceived. Therefore, according to Jewish law, only the offspring of a Jewish mother may be regarded as a Jew. Freezing sperm and pre-embryos is permitted only when all other options have been exhausted to ensure that the father's identity is intact (Schenker, 1997). These are all important considerations when considering ethical treatment options for Jewish couples.

Catholicism.Another example highlighted in the literature which demonstrates the ethical and religious concerns which can be raised when a couple presents for treatment in the hopes of achieving a pregnancy can be further seen in the Catholic Church's stance regarding the *status* of the embryo that is created in ART. The embryo is viewed by the church as *life*, and thus, if there were additional embryos that were not being utilised for a treatment cycle, the church would not deem destroying the surplus embryos as the appropriate thing to do (Fathalla,



2001; Schenker, 1992). Furthermore, the Catholic Church does not agree with techniques that involve gamete donation and fertilisation which takes place outside of the womb (Schenker, 1992). All of which may impact the couple's choices and course of treatment. Islamic beliefs on the other hand, centre on building a family when married and prohibit adoption and donor insemination as alternative solutions to infertility as there are no blood ties to the father (Folkvord, Odegaard, & Sudby, 2005; Inhorn, 2000; Jenkins, 2002; Schenker, 1992; Schenker, 1997). For all these faiths, what is uniformly clear, is that growing the family unit is recognised as a spiritual task. Each, however, has divergent requirements on how to grow the family unit.

The examples of spiritual ideologies that inform understandings of childlessness, and the practices that may be intricately connected, all seem to have one common thread: extending the family unit beyond husband and wife is encouraged. Each has differing vantage points in what they view permissible to achieve that in the light of infertility, and this cannot be omitted in the doctor-couple relationship when factoring in fertility treatment.

Conclusion

Collectively, the bio-psycho-social-spiritual literature provides a saturated understanding of involuntary childlessness and treatment experiences. Each provides unique insights into infertility from an individual level, as well as illuminating how infertility can reverberate and impact the couple and community systems. Together, as if looking into a kaleidoscope, they mutually provide a clearer view of the broader infertility picture.

The next chapter presents the methodology which details the steps and processes followed in executing the research project.



PART C



CHAPTER 4: RESEARCH METHODOLOGY

Hey, Mr. Seeker Hold on to this advice If you keep seeking you will find Don't want to follow Down roads been walked before It's so hard to find unopened doors Are you ready? For what's to come...

"Are you ready?"

(Kurzweg, Marshall, Phillips, Stapp, & Tremonti, 1999, track 1).⁶

⁶ These lyrics spoke to my early research experiences. When I considered conducting research into people's experiences of infertility, a natural question for me was "how will I attempt to access subjective experience?" As the lyrics depict, I wanted to venture down un-walked paths of experience, with the hopes of enriching my own, and others', understanding of fertility treatment experience in the South African public health context.



Introduction

Dagobah, a forgotten, underdeveloped world, characterised by its murky swamp, was the setting for the Jedi Master Yoda, to share his words of wisdom with Luke Skywalker. "Do. Or do not. There is no try." (Kurtz & Kershner, 1980). Much like Luke, I heard these words as if spoken specifically to me when crafting this and other chapters. It reminded me: "submerge yourself.... completely....no matter what." In writing this chapter, I reflected on what felt like, at times, a murky swamp-like research terrain, with very few guides to direct me. I have many balls to juggle in my day, as I would imagine most PhD students do. I am a wife and mother of two young children; I consult five days a week; and four years ago, I added PhD student as a new addition to my identity. I tackle this ball in the evenings and have set days aside in my diary weekly, to dedicate to this research project. Despite the time devoted to my studies, I have always felt like it is not enough for me to get drenched in the "doing" of this project. Ι submerge, and then I need to re-emerge to function in my other roles, all of which I enjoy. As I dry off from my researcher role, thrust into "normal" life, I then need to dive deep again into my role as researcher. So, as I ebb and flow between my researcher, wife, mom, psychologist, and friend roles, I am acutely aware of maximising my contact time with this very important facet of my life: that of research. I have often thought back to how this all began. How did I get here? It reminds me of a question I asked at a narrative workshop I had the privilege of experiencing a few years ago. It was a question that I will never forget the answer! I courageously asked the facilitator during tea time: "How did you prepare for today's workshop?", and he skilfully replied: "I've been preparing my whole life for today". As have I!

What follows is my experience as a novice researcher conducting an IPAresearch project in a public healthcare facility in SA. The intricacies, nuances, steps and processes I followed in executing the research project follows thereafter.

Researcher

I began navigating by reflecting on the beginnings of my tertiary academic life. As an undergraduate student, I was introduced to the world of quantitative research design. Quantitative methodologies immersed me into the culture of an evidence-based, quantitative research terrain, where establishing a hypothesis, research design and rigorous sampling, quantitative data collection and analysis were methods I had to quickly get used to, despite my resistance. My chief critique of quantitative methods at the time (as if I can be so bold as to



critique scientifically established methods), were the very values they praised themselves for, as I understood it: the application of a scientific approach, which attempts to produce valid conclusions by classifying and counting features objectively, with the use of statistical tools to explain what is observed.

Admittedly, the statistical resistance on one level was linked to my irksome relationship with mathematics that developed in secondary school. Somewhere along the line, it became a knotted mess. When learning about quantitative methods at tertiary level, there was the upside that these methods, for the most part, are neatly compartmentalised with fixed boundaries and clear steps on how to execute quantitative research projects. So, learning for examination purposes, for example, was quite straightforward. However, my resistance to quantitative methods resonated beyond the issue with numbers and tapped more into the struggle it placed on my curious self. Quantitative methods seemed to me to not consider "grey areas" as additional research space. I wondered how a participant would experience a questionnaire, for example, that did not provide their answer. Later I learnt that a researcher could develop questionnaires that also provided open-ended questions. However, were all unique answers included as valid data, especially when attempting to prove a hypothesis when a participant's answer may discredit it? I also wondered how some participants experienced the research process? Was their unique experience considered valid? How did they experience the communication of findings? Did they feel heard? Could something the participant shares shed new light on the experience being researched; that if we were to consider it and enquire more, we could learn more and open new doors to experience?

I am aware that I am potentially opening up a can of worms here. That is not my intention. I acknowledge that there are mixed methods, which I feel bridges the gap to a large extent and perhaps makes it an easy exercise to dissolve a large proportion of the humble critique levelled here. What I am acknowledging here is that I had personal difficulty with the epistemological underpinnings of quantitative research paradigms as a whole. To me, expressing findings in numbers was an alien manner in which to express subjective experiences. Perhaps to me, it feels like the identity of the experience is somehow muted down when described in this manner. Kind of like an overly diluted cold drink, that leaves you having a taste, but not actually getting the full impact of the flavour. As Smith, Flowers, and Larkin (2009) eloquently put it, nomothetic approaches collect, convert and analyse data in a way that impedes the retrieval or analysis of the very persons who provided the information at the outset.



I acknowledge that depending on the research project, quantitative methods may be very useful, especially when attempting to report on prevalence studies, for example. When considering this research project, it did not enter my mind to consider a quantitative method. As there has been an abundance of research in health psychology from both qualitative and quantitative approaches, the selection of the methods would be directed by the research question (Pietkiewicz & Smith, 2012; Smith, 2004; Smith, Flowers, & Larkin, 2009). In South Africa, no research has been executed utilising IPA methodology on this subject of interest. This was a magnetising element. Furthermore, other ideologies could provide diverse views on the topic being studied, but the selection of IPA methodology seemed to feel like the one that would most effectively answer the research question.

Was I badgered a little when presenting my research proposal to the Psychology Department at the University of Pretoria? Yes, a little. Utilising a qualitative methodology, which solely employed semi-structured interviews, utilising a small sample, and utilising IPA for a PhD study received some concern. One suggestion related to a concern levelled regarding validity, was to consider backing up my interviews by employing a mixed methods approach, which may settle the concern regarding the validity of findings. The idea put forward was to employ a questionnaire that would also derive statistical data. At that point, I thought "no, no, no!" This was not in keeping with the research position or the intended sample size, which is considered diminutive for those working quantitatively. This proposition had many implications as it was suggested that I consider increasing my sample size significantly, i.e. to have the questionnaire handed to each patient that attends the fertility unit over a set period of time and from there, to correlate the data obtained together with the findings obtained from the interviews, and report on that. What was intended to be a humble PhD study, was in that moment, taking on a new life entirely. A courageous conversation was had, where the theoretical underpinnings of IPA were explained and that I would like to conduct an in-depth analysis of the interviews that I have with the people who agree to participate in the study, even if it meant I had one opportunity to capture part of their experience in that one sitting, due to their unique circumstances. The Psychology Department agreed for the research to go ahead, pending the Faculty of Health Sciences' approval, which I received. It did teach me something, though: No matter what you "Do. Or do not", there will always be something else you could "Try".



Paradigm

Erwin Schrodinger was a 1900's Nobel prize-winning physicist who boldly claimed in one of his works:

The sensation of colour cannot be accounted for by the physicist's objective picture of light waves. Could the physiologist account for it if he had fuller knowledge than he has of the processes in the retina and the nervous processes set up by them in the optical nerve bundles and in the brain? I do not think so (Schrodinger, 1992, p. 154).

This, I thought, was remarkable. A person, trained in empirical methodologies, acknowledged a facet of research (subjective experience), that was all too often neglected or refuted vehemently by his fellow colleagues, due to their epistemological view of the world. I am sure Schrodinger's realisation was not intended to undermine the validity of his evidencebased roots, but he acknowledged, it seems, that quantitative methods are unable to adequately venture to the heart of a person's unique lived experience of a phenomenon. And in that lies the researchable terrain of IPA. This research is situated within a qualitative research paradigm, which I will explain in more depth regarding the ontological and epistemological nuances below, before exploring the methodology in more detail later.

Ontology

IPA has a relativist ontology which is concerned with subjective experience. Reality is viewed as subjective, and therefore, lived experience is seen as an interpretive process which is unique to each individual. The ontological focus is on individual subjective experience and on the uniqueness of that experience (Dowling, 2007; Dukes, 1984; Smith, 2010; Smith & Osborn, 2003). As an IPA researcher, the focus was not on what participants consciously knew, but examined how participants made sense of their fertility treatment experiences within the public healthcare context. Each couple's unique contexts inform the researchable ontological terrain.

Epistemology

IPA has an emic epistemology, and as such, allows the researcher to enter the participant's context, in an attempt to understand experiences from the participant's point of view (Morris, Leung, Ames, & Lickel, 1999). To help illustrate this epistemological stance, I refer to Madill, Jordan, and Shirley's (2000) discussion of objectivity and reliability in qualitative analysis.



Their discussion of what they called the "contextual constructionist position" seems to help illuminate the subjective epistemological tenants of IPA. According to the contextual constructionist position, three aspects mediate the production of knowledge: the participant's understandings and interpretations of experience; the researcher's interpretations of the participant's interpretations; as well as cultural aspects that pertain to the research. From the contextual constructionist position, the researcher is less concerned with evaluating their research against quantitative criteria of objectivity and reliability, but will argue that results will differ due to the context in which the data was collected and analysed. IPA research, and with that, knowledge production, is subjective, where different accounts of the same phenomenon are not invalidated by different viewpoints. Rather, research findings should be grounded within the accounts that have given rise to them in order to preserve quality. Therefore, although the researcher uses their own personal biases and previous knowledge to understand participants' interpretations of their experiences, reflexivity is an important component of all IPA research (Madill, Jordan, & Shirley, 2000; Smith, 2004; 2008; 2010).

Methodology

Rigorous research methodologies utilised in evidence-based healthcare, have most often referred to or implied those offered by quantitative methods (Biggerstaff & Thompson, 2008). However, the advent of equally rigorous qualitative methodologies, such as IPA, has made it possible to venture closer to patients' understanding and interpretation of their lived experiences. When considering focusing on health and healthcare from the viewpoint of the patient, it is imperative to utilise appropriate and reliable methods to meet the research aim (Biggerstaff & Thompson, 2008). In health psychology, the researcher seeks to understand the meaning and significance of a particular condition on a person's everyday life, and would be interested in in-depth accounts of individuals' experiences (Pietkiewicz & Smith, 2012; Smith, 2004; Smith, Flowers, & Larkin, 2009). IPA offered the opportunity to develop an idiographic understanding of the research participants, and what it means to them within their social context, to undergo fertility treatment in a public health care facility. As a qualitative methodology, IPA promotes an inductive approach to data collection and analysis, and therefore refutes the formulation of hypothesis prior to conducting the research.

The methodology adopted in any research project should have the core purpose of best answering the research question. As I see it, the research question gives the coordinates of the research project, guiding the mode and method of transport of the research terrain. The research



question is very specific, with the view of eliciting contextual interpretations of the phenomenon being researched. The question that this project endeavoured to answer was: "How do couples who have been diagnosed with primary infertility make sense of their experiences of fertility treatment within the South African public health sector?" IPA was selected as the most appropriate methodology with which to answer the research question, due to its commitment to the detailed exploration of subjective experience and the methods used in order to achieve this aim (Biggerstaff & Thompson, 2008; Lawler, 1998; Lopez, 2004; Mackey, 2005; Smith, 2010; Smith & Osborn, 2003).

The literature review was conducted prior to the research study in order for me to familiarise myself with the topic and to attempt to gain valuable insights into the phenomenon. As a result of prior reading, the researcher's knowledge of the phenomenon is enhanced, and can be applied when making decisions regarding the data collection method, which was the case for this project. The researcher's knowledge and expertise are therefore viewed as valuable in the research process (Lawler, 1998; Lopez, 2004; Mackey, 2005; Smith, 2010; Smith & Osborn, 2003).

IPA is a methodological approach to qualitative research that was used as a distinctive research method in Psychology in the 1990's, and was developed by Jonathan Smith within the discipline of Psychology (Smith, Harre, & Van Langenhove, 1995). As a qualitative research approach, it is now also being utilised within the human, social and health sciences, to explore the human experience. The primary goal of an IPA researcher is to explore how individuals make sense of their life experiences (Biggerstaff & Thompson, 2008; Pietkiewicz & Smith, 2012; Smith, 2008; Smith, Flowers, & Larkin, 2009). Individuals are viewed as "self-interpreting beings", who are continuously engaged in interpreting the events, objects, and people in their lives (Taylor, 1985). Therefore, this research approach allows for in-depth exploration of idiographic subjective experience, and draws upon the principles of phenomenology, hermeneutics, ideography (Pietkiewicz & Smith, 2012; Smith, 2012; Smith, Flowers & Larkin, 2009), and symbolic interactionism (Eatough & Smith, 2008).

IPA is a highly compatible approach with research that centres on the uniqueness and meaningfulness of a person's experiences. IPA is concerned with what the experience for the participant is like, what sense the participant is making of what is happening, in the hopes of



revealing something of the experience of the participant (Pietkiewicz & Smith, 2012; Smith, 2004; Smith, Flowers, & Larkin, 2009).

I would like to briefly sketch out the theoretical underpinnings of IPA before moving to a comprehensive discussion of the IPA methodology employed here.

Foundations of Interpretive Phenomenological Analysis (IPA). How do we make sense of IPA in light of the philosophies that have informed its inception? IPA draws on aspects of the philosophical principles of phenomenology, hermeneutics, and ideography, and is also influenced by symbolic interactionism, informing its distinctive epistemological framework and research methodology (Eatough & Smith, 2008). I will discuss the origins of IPA by attending to the interpretive component first, followed by the phenomenological and concluding with the analysis component.

Interpretive Phenomenological Analysis (IPA). IPA is interpretive, in recognising the researcher's role in making sense of the experience of participants. A double hermeneutic is employed, where the participant tries to make sense of their personal and social world, and the researcher tries to make sense of the participant trying to make sense of their personal and social world. Researchers access participants' experiences through their accounts of the experience. The double hermeneutic implies the researcher's involvement in interpretation by acknowledging that the researcher brings their own preconceptions and prejudices to the interpretive process and must be mindful that these can be obstacles to interpretation unless priority is given to the phenomenon being investigated (Smith, 2004).

IPA is concerned with trying to understand what it is like from the point of view of the participants. A detailed IPA enquiry involves asking critical questions of participants' accounts. Therefore, interpretation requires a critical and questioning approach, in a manner that opens up space for participants to consider their experiences in ways they may not have been able to before (Eatough & Smith, 2006; Eatough & Smith, 2008).

Smith (2004) employs two of Ricoeur's (1970) strategies for understanding meaning. The first being a hermeneutics of meaning recollection (empathic engagement) and the second being a hermeneutics of suspicion (critical engagement). Smith (2004) argues that both modes of hermeneutic engagement can contribute to an in-depth understanding of the participant's



lived experience, where empathic reading usually comes first, followed by a critical and speculative reflection (Smith, 2004). Smith, Flowers, and Larkin (2009) state that IPA occupies a "centre-ground position" making it possible to combine a hermeneutic of empathy with a hermeneutic of questioning, when the intention is to draw out the meaning of experience.

Interpretive Phenomenological Analysis (IPA). Interpretive Phenomenological Analysis (IPA) is phenomenological in its detailed examination of personal lived experience of people's engagement with the world (phenomenon), and in exploring how participants make sense of their lived experience of phenomena. IPA is dedicated to researching the subjective experience of something which is of particular significance to the person. It is concerned with what makes an ordinary experience become an "experience" that is important to the participant. IPA recognises that the understanding of an event or an object is always mediated by the context of cultural and socio-historical meanings. *Lived experience* encompasses the embodied, socio-cultural and historical context of the research participant, who we acknowledge lives in an intentionally interpreted and meaningfully lived world (Eatough & Smith, 2006; Eatough & Smith, 2008). In agreement with Heidegger's (1962) views on interpretation, phenomenological enquiry is viewed as an interpretive process, where interpretation is necessary because the object's mode of appearing may mask something that is hidden.

As can be noted, phenomenology has a strong philosophical component (Moran, 2000). When applied to this study, the following phenomenological characteristics, as they apply to IPA, had bearing on my selection of an IPA approach:

- (i) The importance and relevance of a focus on experience and perception.
- (ii) Acknowledges experiences as being conscious.
- (iii) Focuses on how participants come to their unique understandings of their world.
- (iv) IPA emphasises the pertinence of reflective practice. Deliberate reflection on experience is encouraged in IPA research. It is a process that both the participant and the researcher engage in. The participants in this project reflected on their ongoing experiences of fertility treatment. I engaged in an ongoing reflection and interpretation of participants' interpretations, as well as an ongoing reflection on my own process. With reference to this project, reflection was continuous: beginning before, spanning during and continued in the writing up of the research. Reflection on the participants' narratives, as well as on my own experiences as researcher and practitioner throughout the research



process, refers to a meta-reflective process, which involves reflection-in-action, reflection-on-action, and reflection-for-action (Maree, 2013). Applied to this study, reflection-in-action is represented in the prologue of the research report, reflection-on-action is demonstrated by the research findings, which encompass participant reflections on experience and my sense-making of their reflections of fertility treatment experience, and reflection-for-action is demonstrated through the epilogue of the research report. Meta-reflection leads to a higher level of understanding where reflection is more of a reflexive practice (Finlay & Gough, 2003; Maree, 2013).

Interpretive Phenomenological Analysis (IPA). IPA is ideographic due to its focus on the detailed examination of particular instances of lived experience in single case studies, or small group studies. The analytic process begins with the detailed analysis of each case, moving to similarities and differences across cases to produce accounts of patterns of meaning and reflections on shared experience. Connecting the research findings to existing psychological literature assists the reader in relating the case to other relevant research, while at the same time allowing individual nuances to be illuminated (Smith, 2004; 2008; 2010; Smith, Flowers, & Larkin, 2009).

The ideographic argument for a focus on the particular, and with that, consideration for the importance of single case studies, seems to be the tenets that IPA has absorbed. IPA adopts analytic procedures for moving from a single case to more general statements, which still allow for the retrieval of particular claims (Smith, 2004; 2008; 2010; Smith, Flowers, & Larkin, 2009).

A key aspect of IPA is that the process of analysis is iterative, that is, that we move back and forth through a range of different ways of thinking about the data, as opposed to completing a range of steps sequentially. The moving back and forth process would create a shift in one's relationship to the data according to the hermeneutic circle. Therefore, my entry into the meaning of text can be made at any point, at several different levels, where these levels relate to one another and many of which will provide different perspectives on the part-whole coherence of the text (Smith, Flowers, & Larkin, 2009). Analysis of data is a process of interpretation based on co-creation and interpretation. A double hermeneutic is employed where the participant makes sense of their experiences, and the researcher makes sense of the participants' sense-making with the desired outcome being to learn about the participants'



unique contextual interpretations of subjective experiences (Mackey, 2005; Smith, 2010; Smith & Osborn, 2003; 2007).

When considering IPA, as I understand it, phenomenology defines the aims of IPA, which centres on uncovering the interpretations and understanding that people have of their experiences of a phenomenon. Hermeneutics is the tool of IPA, which describes the way in which we interpretively engage with the data. Lastly, ideography defines the way that findings are revealed and *how* themes emerge from the data (Madill, Jordan, & Shirley, 2000; Smith, 2004; 2008; 2010).

IPA synthesises ideas from phenomenology and hermeneutics, resulting in a method that is interpretive as it is believed that there are no such things as uninterpreted phenomena.

IPA research encompasses three "I's":

- (i) It is ideographic, providing a detailed analysis of each case by examining how people make sense of their personal and social world (Smith, Harre, & Van Langenhove, 1995).
- (ii) It is inductive, where themes emerge from the data, as opposed to testing against a hypothesis based on current literature (Smith, Harre, & Van Langenhove, 1995); and
- (iii) It is interrogative, where it is viewed in relation to existing literature as opposed to in isolation. Discussion of findings in relation to the literature review can be viewed as an extension of the analysis (Smith, Harre, & Van Langenhove, 1995).

Axiology

The role of values is recognised and acknowledged in IPA research. I actively acknowledged my own interpretations and biases that I may have had when conducting the research. This principle was maintained throughout the entire research project, from the time of interviewing through to the conclusion of the thesis (Creswell & Clark, 2011; Finlay & Gough, 2003; Maree, 2013; Smith, 2004; Smith, Flowers, & Larkin, 2009).

Rhetoric

The research report takes an informal linguistic style. The research has been written up in a literary, informal manner. This research project followed an informal linguistic principal in an attempt to convey the couples' experiences in an authentic manner (Creswell & Clark, 2011; Smith, Flowers, & Larkin, 2009). Findings derived from couples' narrations of their



experiences were shared in a conversational manner, in keeping with both the style of the interviews and IPAprinciples (Ponterotto, 2005; Smith, 1991; 2008; 2010; Smith, Flowers & Larkin, 2009; Zahavi, 2008).

Methods

Smith, Flowers, and Larkin (2009, p. 41) ask us to imagine methods of an IPA research project as providing a "map of the territory which we wish to cross". I begin by delineating the research phases (see *Figure 5*), giving the reader a global view of the steps taken throughout the research process. This is then followed by a detailed account of data collection, transcription, and analysis procedures.

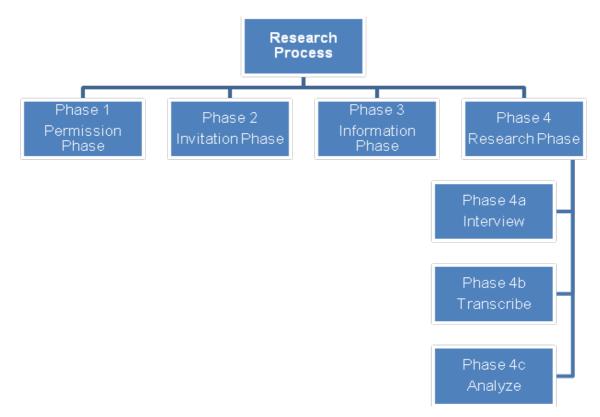


Figure 5: The research process depicting research phases 1-4.

Permission Phase

In order to gain access to potential research participants for this project, I engaged with key role players at Steve Biko Academic Hospital (SBAH) requesting permission to conduct the research in the Reproductive and Endocrine Unit. It was after numerous meetings, detailing the nature and aims of the research, explaining methods of data collection and how the research will be reported, that permission was granted to conduct the research at the SBAH (see Appendix B).



The Reproductive Specialist alongside whom I worked, as well as the head of the Reproductive and Endocrine Unit, were kind enough to allow a "stranger" onto their medical turf. These specialists graciously talked me through the unique services and contributions this public health facility provides its patients. In the very early phases of the research being a mere "idea" and still at the "gaining access phase", the head of the Reproductive and Endocrine Unit was kind enough to provide a guided tour of the Unit and presented, as far as possible, the different technologies that are utilised in the magic they have the potential to create on a daily basis. The passion, empathy, and conviction expressed and felt when talking about the important roles and functions the staff fulfil daily, made this special Unit, the right fit for the project. I was and still am, humbled that I was allowed to be a visitor to the Unit over the eight months I conducted interviews there.

I met with a key person in the Department of Obstetrics and Gynaecology (which forms part of the University of Pretoria) at SBAHto discuss the aims of the research project, and the kind of data that I was looking to collect. I now needed access to the sample population, and this is where SBAH would be pivotal due to their patient population (detailed in the subsequent section). It was approved that this research project could be conducted from within the Reproductive and Endocrine Unit of the Department of Obstetrics and Gynaecology at SBAH. The Reproductive and Endocrine Unit provides diagnostic and Artificial Reproductive Technology (ART) services and is also an accredited training unit for clinical technologists and medical biological scientists in Reproductive Biology (Huyser & Boyd, 2013). What is mostly a scientific environment now had an additional lane: the psychological investigative avenue.

The process for approval required that the project complied with the ethical and academic guidelines as set out by the Department of Psychology of the Faculty of Humanities at the University of Pretoria (UP), and Faculty of Health Sciences at the SBAH. Upon ethical clearance from both faculties, the research project then became a reality to me. I could now go and talk to people regarding their experiences of infertility treatment.

Invitation Phase

I worked closely with a reproductive specialist at the Reproductive and Endocrine Unit at SBAH. I provided her with the research "Invitation Letter" (See Appendix C), as she was the first point of contact with potential research participants. It was during her initial



consultation with new patients, that the "Invitation Letter" could be provided to the potential participants who met the research criteria (which I discussed earlier on page 109).

The reproductive specialist identified couples from those she treated for infertility and provided the couple with the researcher's "Invitation Letter". When participants agreed, they read and signed the document in her presence. After agreeing to participate in the project, they met with me directly after their consultation with the specialist, for the information phase, discussed next.

Information Phase

Subsequent to the invitation phase, the introduction letter was discussed with the potential participants, and the scope of the project was delineated. Informed consent was a necessary condition to participation in the research project. A consent form (Appendix D) was given to each participant, which they read and signed when they agreed to participate. Any questions that the participants had were addressed in the meeting in order for consent to be an informed decision.

Participants

Sampling criteria. In some ways, I felt like a reporter with a hot lead but no real grassroots experience of the context. In this regard, it was important for me to establish a contextual understanding of the REUat SBAH and its procedures, as well as to familiarise myself with the population that seek assistance at the REU. In 2012, I spent some time with both the reproductive specialist with whom I worked closely and the head of the REU to become acquainted with the workings of the unit. When it came to this project, I wondered what the participants would look like. Not physically, but rather what criteria could be set in order to gain access to a sample that would best answer the research question?

In order to participate in this study, the following criteria needed to be met:

- (i) The couples were required to be in a co-habit or marital relationship;
- (ii) Both partners in the relationship needed to be willing to participate in the study;
- (iii) The couples needed to be South African citizens as this study enquired about South African couples' experiences and would be conducted in a South African context;
- (iv) The couples had to be able to express themselves in either English or Afrikaans;



- The couples had a clinical diagnosis of infertility made by the reproductive specialist at the REU;
- (vi) The diagnosis made by the reproductive specialist needed to be primary infertility.
 Primary infertility denotes the failure to achieve pregnancy after at least twelve months or more of unprotected sexual intercourse (Gurunath, Pandian, Anderson, & Bhattacharya, 2011; Marchbanks, Petersen, & Rubin, 1989; Zegers-Hochschild et al., 2009) and indicates that the couple has no children whatsoever;
- (vii) The couple needed to be actively engaging in fertility treatment cycles. Irrespective of the fertility treatment chosen for the couple by the reproductive specialist, each couple would be interviewed after each treatment cycle, for the duration of their treatment, not exceeding three treatment cycles;
- (viii) The reproductive specialist would be the first point of contact with potential participants. The first eight couples who met inclusion criteria a-g, as set out above, and who agreed to participate in the project, would be selected.

Sampling method. Recruiting participants for an IPA study requires that participants are selected purposively, based on specific features or characteristics enabling a detailed exploration of the phenomena being studied. Samples are typically homogenous, where participant selection is guided by the research question as being meaningful to those participants in particular. The investigation of the phenomenon may in itself define the boundaries of the relevant sample (Pietkiewicz & Smith, 2012; Smith, 2004; Smith, Flowers, & Larkin, 2009). This research project made use of purposive sampling which looked at selecting those people who fit the criteria set for the research project.

Research participants. A reproductive specialist at the REU assisted me with selecting prospective participants who complied with the inclusion criteria for the project (Brocki & Wearden, 2006; Henning, Van Rensburg, & Smit, 2004; Osborne, 1994; Pietkiewicz & Smith, 2012; Smith, Flowers, & Larkin, 2009; Terre Blanche & Durrheim, 2002).

While there is no hard-and-fast rule regarding the number of participants that should be included in an IPA study, more often than not a strong case is made for small sample sizes because the primary concern is with providing a detailed account of individual experience (Smith, 2008; Smith, Flowers, & Larkin, 2009). Sample sizes can be dependent on the research question and the quality of data obtained. IPA studies have been published with as little as one



participant to as many as fifteen. Turpin et al. (1997) state that clinical psychology doctoral programmes in Britain recommend that six to eight participants are appropriate, where similarities and differences between individuals can be explored (Pietkiewicz & Smith, 2012). Small sample sizes and single case studies can be justified when the researcher has a particularly compelling case (Barker, Pistrang, & Elliot, 2002; Brocki & Wearden, 2006; Henning, Van Rensburg, & Smit, 2004; Langdridge, 2007; Pietkiewicz & Smith, 2012; Smith, 2008; Smith, Flowers, & Larkin, 2009; Terre Blanche & Durrheim, 2002). This project explored the experiences of eight couples who have been formally diagnosed with primary infertility and who were actively engaging in fertility treatment at the REU. Table 1 below, provides biographical information for each of the participants.

Couple	Participant 1 ⁷	Age	Race	Gender	Length of Conception
					Difficulties
Couple A	Participant A1	24	Indian	Male	2 years
	Participant A2	25	Indian	Female	
Couple B	Participant B1	28	Black	Female	8 years
	Participant B2	32	Black	Male	
Couple C	Participant C1	30	Black	Female	1 year
	Participant C2	33	Black	Male	
Couple D	Participant D1	30	Black	Male	1 year
	Participant D2	23	Black	Female	
Couple E	Participant E1	28	Black	Male	4 years
	Participant E2	30	Black	Female	
Couple F	Participant F1	35	Black	Female	9 years
	Participant F2	44	Black	Male	
Couple G	Participant G1	27	White	Male ⁸	4 years
	Participant G2	22	White	Female	
Couple H	Participant H1	27	Black	Female	4 years
	Participant H2	29	Black	Male	

Table 1: Participant Demographic Information

⁷ Participants were numbered according to which of the participants first initiated conversation in the interview.

⁸ At the time of the interviews, Participant G1 was undergoing gender reassignment - transitioning from female to male. I have assigned the participant as "male" as this is how the participant personally makes sense of his gender.



Research Phase

During the information phase, appointments, as far as possible, were set up for the research interviews. Some couples were available straight away, while others had to go back to work directly after their appointment with the fertility specialist. In those cases, tentative appointments were made and a follow-up telephone call was made to confirm the interview appointment.

Interviewing the participants. Data collection methods in IPA research are fundamentally focused on inviting participants to offer rich, detailed, first-person accounts of experiences. Aside from semi-structured interviews, alternative methods for rich data collection are diaries, focus groups, email conversations and letters. Data collection is often carried out through semi-structured, one-on-one interviews, which allow for in-depth idiographic investigation of how participants are making sense of experiences. These interviews are usually an hour or more in duration, which are audio recorded and transcribed verbatim (Pietkiewicz & Smith, 2012; Smith, 2004; Smith, Flowers, & Larkin, 2009).

The researcher utilising a semi-structured interview method, engages in conversation with the participant in such a way that allows questions to be modified as the conversation unfolds, and gives space and flexibility for tracking the unique aspects that arise during the interview. Pietkiewicz and Smith (2012) emphasise the importance of the researcher's interview skills: Rapport building is highlighted as an important aspect of the interview process as gaining the trust of the participant may reduce the tension around speaking about their personal experiences. Active listening and having the ability to ask open-ended questions are further highlighted as important components to an interview process that is more likely to encourage a free-flowing conversation (Pietkiewicz & Smith, 2012; Smith, 2004; Smith, Flowers, & Larkin, 2009).

When thinking of embarking on a semi-structured interview, it is advised to prepare an interview schedule that will guide the conversation, which may enable the researcher to explore key areas the researcher wants to investigate. IPA studies may concentrate on exploring sensory perceptions, mental phenomena such as memories, thoughts and fantasies, as well as individual interpretations. The interview schedule can assist novice researchers like myself, to have a good idea of the areas we would like to cover, but can also assist as prompts in the case where participants may find certain questions too broad. During the interview process, the researcher should be comfortable with silences, and be acutely aware of all verbal, non-verbal and non-



behavioural communication (Eatough & Smith, 2008; Pietkiewicz & Smith, 2012; Smith, 2004; Turner, Barlow & Ilbery, 2002).

As the interview unfolds, the researcher should be sensitive to the emotional reactions of the participant. Should it be noted that the participant displays signs that the interview is creating uncomfortable emotional reactions, the researcher may need to use counselling skills to manage the impact of the interview on the participant. The researcher should follow ethical procedures, such as referring the participant for counselling, should the researcher feel it is indicated (Pietkiewicz & Smith, 2012).

In this study, couples were interviewed using a semi-structured interview schedule (Appendix E). This type of interview method allowed me to modify questions in response to participants' responses, and it afforded me the flexibility to explore important areas as they arose. Moreover, it contributed to establishing rapport with the participants as conversations took a natural flow, as opposed to keeping to a rigid set of questions that needed to be addressed. This left room for generating richer data (Neuman, 2000; Smith, 2008; Smith, Flowers, & Larkin, 2009; Terre Blanche & Durrheim, 2002).

As the guidelines apply to this study, the investigation of infertility treatment experience in the South African public health sector meant that certain parameters that were initially set out, needed to be revisited as the unique circumstances of each couple's fertility treatment path unfolded. This meant that my initial idea of tracking eight couples' fertility treatment cycles, for at least three full cycles was not always possible. The reasons for this are many, most of which were due to: financial constraints that hindered their ability to continue with fertility treatment; the disruption the fertility process had on the couple's work schedule; emotional difficulty with fertility treatment process leading to the suspension of treatment; while others fell pregnant naturally. All of the reasons for adjusting the trajectory of the research process are in themselves research findings, but also provide feedback regarding the research process in that one needs to accommodate the unique picture the couple presents and accept that sometimes this is how far the couple and the research can go. In that sense, the processes ran parallel to one another.

Below is a visual representation of how some of the interviews were conducted (see *Figure 6*). As stipulated above, certain participants were unable to provide a third and fourth



account of their fertility treatment experience due to their unique circumstantial factors. *Figure* 6below gives the reader an understanding of the interview process employed in this project.

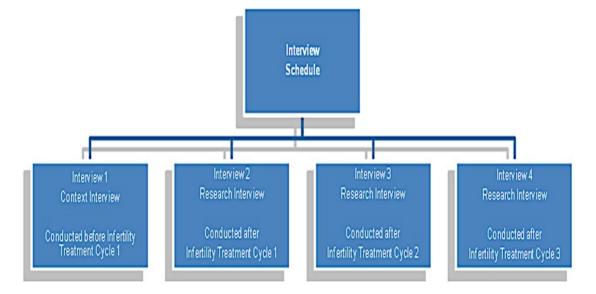


Figure 6: Interview schedule.

Interviewing venues. The research interviews took place in an office at the SBAH following each of the couples' fertility treatment cycles.

Interviewing process. The duration of the interview was no shorter than 60 minutes and no longer than 120 minutes per couple (see Table 2). The initial idea was that the partners were interviewed in each other's presence as follows:

Interview procedure	Duration
Introduction Partner 1 and Partner 2 introduces themselves to researcher	10 minutes
Interview Partner 1 The researcher interviewed Partner 1 in the presence of Partner 2	40 minutes
Reflection The researcher, Partner 2 and Partner 1, had the opportunity to reflect on the interview with Partner 1	10 minutes
Interview Partner 2 The researcher interviewed Partner 2 in the presence of Partner 1	40 minutes
Reflection The researcher, Partner 1 and Partner 2, had the opportunity to reflect on the interview with Partner 2	10 minutes
Conclusion Partner 1, Partner 2 and researcher conclude interview	10 minutes

Table 2: Interview Process



Depending on the couple, some were interviewed as set out above, whilst other interviews were very conversational, where each partner would seem to elaborate on what the other had been talking about. As I reflect on the interviewing process now, the active exchange between partners seemed to provide an opportunity for each partner to *witness* their loved one's unique experiences. It provided a time and place for each partner to share with the other, their feelings of where they were at with things. It provided an opportunity to talk and listen, which became a novel part of the treatment experience for couples (see Chapter 5 findings). It further provided an opportunity for an additional witness to reflect on participants' experiences, as well ask questions regarding their experiences that they had yet to explore. In this respect, the interview provided the couplesystem with an opportunity to hear their experiences from an additional witness, and for them to further explore on an individual and couple level, their experience of infertility treatment (Carey & Russel, 2003; Walther & Fox, 2012).

Interviewing structure. The initial interview was the platform for rapport building and to gain contextual insight into the couples. Utilising the interview schedule as a guide only, I tried as far as possible to track where the participants were taking me as they detailed their history, allowing for a conversational approach to interviewing. I found that this style, allowed all of us to feel more at ease, and provided interviews that took their own course. I utilised questions from the interview schedule when it seemed to me that information that was shared was unclear, lacked detail or an important area of their background had not been attended to. The purpose of the research interviews was to allow the participants to narrate their experience of each of the fertility treatment cycles.

For the majority of the interviews, the aforementioned structure was a guide only. Perhaps more than anything, keeping me aware that both partners' experiences should be attended to. It must be noted that if either of the partners were uncomfortable with being interviewed jointly or explicitly stated that they are uncomfortable being interviewed in their partner's presence, flexibility was exercised during the interview to accommodate for the interviews separately. One such occurrence happened with Couple B (i.e. Bernard and Zethu), where Partner 2 (Bernard) became uncomfortable with his partner's response to a research question and he elected to leave the interview. He later returned to the interview when he was less emotional.



Transcribing the interviews. A requirement of IPA research is that there is a verbatim record of the data collection. In the case where an interview is conducted, a digital dictaphone or video media is required to capture the data (Smith, Flowers, & Larkin, 2009). I utilised a digital dictaphone to record the interviews for use in the research project. Consent to use a dictaphone was received from each of the participants prior to conducting the interviews. I transcribed the interviews verbatim, with a resultant transcript of each interview showing all words spoken during the interview, as well as noted non-verbal utterances, such as laughing, significant pauses and hesitations. Pseudonyms were utilised for anonymity purposes throughout transcription, analysis, and writing up of the thesis (Neuman, 2000; Smith, 2008; Smith, Flowers, & Larkin, 2009; Terre Blanche & Durrheim, 2002).

Consistent with the IPA the interviews were transcribed by me, as transcription of the interviews provided an additional contact session with the data (Easton, McComish, & Greenberg, 2000; Pietkiewicz & Smith, 2012; Smith, 2008; Smith, Flowers, & Larkin, 2009). Pseudonyms were utilised for anonymity purposes throughout transcription, analysis, and writing up of the thesis (Neuman, 2000; Smith, 2008; Smith, Flowers, & Larkin, 2009; Terre Blanche & Durrheim, 2002).

Analysing the interviews. When it comes to data analysis, IPA provides flexible guidelines to assist the researcher in achieving his or her research objectives. The guidelines can be adapted by the researcher, and are therefore not a recipe for analysis (Smith, 1991; 2008; Smith, Flowers, & Larkin, 2009). The researcher, guided by the objectives of the study, should be flexible and creative in their approach to data analysis. Analysis in IPA is an iterative process requiring total immersion in the data (Smith, 1991; Smith, 2008; Smith, Flowers, & Larkin, 2009). The researcher is required to produce evidence of the participants making sense of the phenomena being studied, as well as documentation of the researcher's sense making (Pietkiewicz & Smith, 2012).

Consistent with the IPA method, I utilised the flexible guidelines as suggested Smith, Flowers, and Larkin (2009). Guided by the objectives of the study, I adapted my approach to data analysis. Keeping in mind that IPA data analysis is an iterative process, requiring total immersion in the data, my task was to produce evidence of the participants' making sense of their fertility treatment experience, as well as to document my sense-making (Smith, 1991; Smith, 2008; Smith, 2010; Smith, Flowers, & Larkin, 2009). Even though the practice of



analysis is iterative and multi-directional, for the ease of explanation, I will describe the process of analysis by means of isolating four distinct stages that I applied in this research project:

Initial stage: Multiple reading and note making. I commenced the analysis by reading and re-reading the transcripts multiple times to become completely immersed in the data. I listened repeatedly to the audio recordings, which allowed me the opportunity/opportunities to become fully immersed in the data. Each reading and listening experience provided me with the opportunity for the development of new possible insights. I made notes regarding observations, reflections of the interview, thoughts or comments that occurred to me and that I thought may have significance to the study. Initial interpretive comments were noted, and I also set aside time to reflect on how my personal characteristics (such as gender, age, and social status), may impact the research context with regards to establishing rapport with the participants (Pietkiewicz & Smith, 2012; Smith, 1991; 2008; 2010; Smith, Flowers, & Larkin, 2009).

Second stage: Transforming notes into emergent themes. This stage required that I work with my notes with the view of transforming the initial notes into emerging themes. My task at this stage of analysis was to formulate concise phrases that contained enough particularity to remain grounded in the text and enough abstraction to offer psychological conceptualisation. While focusing on the text, I recognised that I may have already been influenced by having already analysed the transcript as a whole. Acknowledging this is an example of the hermeneutic circle discussed earlier in this chapter, where the part is interpreted in relation to the whole, and the whole is interpreted in relation to the part (Pietkiewicz & Smith, 2012). I noted these reflections as I became aware of them, in an attempt to bracket these possible influences (Smith, 1991; 2008; Smith, Flowers, & Larkin, 2009).

Third stage: Looking for relationships between themes. This stage was concerned with examining the whole transcript for emerging themes. Once themes had been identified, this was followed by clustering themes according to conceptual similarities and providing each cluster with a descriptive label. Themes were compiled for the whole transcript prior to me looking for connections. A list of superordinate themes and subthemes was tabled. Major themes and subthemes, with accompanying short extracts from the transcript, were followed by the line number, so that it was easy to return to the context of the extract in the transcript. The table ensured as far as possible, the preservation of the integrity of what the participant had



shared. This process was repeated for each participant. I recognise that the analysis of the first case may have influenced further analysis, but in keeping with IPA's idiographic commitment, it was important to attempt to reflect on the ideas and concepts which emerged in the first case. I did have an awareness and acknowledgement of the influence that prior analysis I had done on cases before, may have had on the analysis at hand. This was always in my foreground. I tried to keep an open mind to allow emergent themes to develop independently for each case (Smith, 1991; 2008; Smith, Flowers, & Larkin, 2009).

Once all transcripts were analysed, with an accompanying table of themes, a final table of themes was compiled for the study as a whole, by reviewing the tables of themes for each case. The process required repeated returns to the data to check meanings. When deciding on the themes that would be reported, I carefully considered the prevalence of the data, as well as the richness of the extracts and their capacity to highlight the richness of those themes.

Final stage: The narrative account. The final table of themes provided the basis for compiling a narrative account of the research findings. This account consisted of the interplay between the participants' account and my interpretive account. I wrote up each of the superordinate themes, beginning with describing and exemplifying them with extracts from the interview. I then followed this by providing analytic comments. The table of themes now became a narrative that explained the important experiential things that were found during the analysis process. I used the participants' own words to illustrate themes, so that the reader could assess the pertinence of the interpretations, as well as to provide an opportunity to give voice to the participants' personal experience. The narrative account, therefore, includes participants' accounts of his or her experience, using their own words, alongside my interpretive commentary. Writing up the study included basic interpretations of data, as well as a detailed, high-level interpretative and theoretical reflection. The aim was to provide new insights into the experience of fertility treatment in a public health facility.

Reporting the findings. The findings of this research project were explicated in this PhD publication, and will also be submitted for a peer-reviewed journal article. The writing commenced with a close reading of the participants' accounts, before moving towards an interpretive level. I attempted to report the findings in a way that I thought would be accessible and appealing to the reader. Included in the write-up, are various extracts from participants' interviews, coupled with my interpretive comments. This retained the participants' voice while



simultaneously providing the reader with the opportunity to assess the pertinence of the interpretations made (Smith, 1991; Smith, 2008; Smith, Flowers, & Larkin, 2009). In this regard, I feel that the reader then becomes an additional *witness* to the research, as each reader may have supplementary insights when reviewing the research findings (Carey & Russel, 2003; Walther & Fox, 2012).

Quality

Guidelines

Specific guidelines for assessing the quality of IPA studies have been outlined by Smith (2010) and were utilised in the revision of this research project by the peer review group. The guidelines that were employed are as follows: Firstly, assess whether the research has a clear focus. Secondly, determine whether the research project has gathered strong data, which is derived from the examination of data collected from each interview. Thirdly, the research should highlight the prevalence of themes that have been identified through the use of extracts from the interview data. This will highlight convergence and divergence, variability and representativeness within the study. Fourthly, the analysis of data should be interpretive and not solely descriptive. Interpretations should follow the extracts which describe the emergent themes. Lastly, the thesis needs to be written carefully. The reader should feel they have a detailed understanding, of the phenomenon being investigated, once they have read the research findings, which I feel I have achieved (Smith, 2010).

Journal

I kept a research journal, documenting my personal experiences of each stage of the research project and my reflections both personally and academically. Keeping a journal is in line with IPA research which encourages researchers to be aware of their own experiences and the influence the researcher has in the research process. Documenting my own personal reflections provided a space and time for me to reflect on the research process, each step of the way. I wrote following each interview with a couple. I remember one instance, where I heard a couple that I was waiting to interview in the waiting room. They playfully joked with one another, making light of things as they waited to first see the doctor and then me. I noted my thoughts and feelings on occasions such as those and following each contact session with participants. The journal also became a place where I reflected on the research process. Many reflections and questions centred on my role as a researcher and at the same time, as a



psychologist. For example, how would these interviews have gone differently had these people come to see me for a consultation? How would I have asked questions differently? How would I have managed certain moments in the interview differently if my role was of psychologist? Would the interviews have been different or was I managing the researcher role within the backdrop of a psychological context?

The journal was helpful on many levels, providing an opportunity to share additional insights as well as a way for me to check myself and to ask myself if this interpretation is mine, theirs, or a second hermeneutic interpretation. Therefore, the journal served a threefold function in this study: the first, was an opportunity for self-reflection; the second, an opportunity to reflect on the research process; and the third, was to reflect on sense-making (mine, participants, or my sense-making of their sense-making).

Supervision

I made use of an analytic auditing method to check the credibility of the research results (Barker, Pistrang, & Elliot, 2002; Krefting, 1991). Firstly, I attended frequent contact sessions with my supervisor for the project to discuss each phase of the project. Secondly, I forwarded all aspects of the research project that had a medical reference, to the co-supervisor for the project, who has specialist medical expertise in infertility treatment. This ensured that all medical information presented in the thesis was medically accurate. Thirdly, I engaged in a peer review process, which involved contact sessions with fellow PhD students, who assisted in checking the analysed material against the originally transcribed data, to validate the research findings (Barker, Pistrang, & Elliot, 2002; Hames, 2007; Krefting, 1991).

Ethics

Research Permission

Requesting permission to conduct the research project involved receiving permission from SBAH, the Department of Psychology of the Faculty of Humanities, and the Faculty of Health Sciences at the University of Pretoria (UP) (detailed on page 113 under the heading Permission Phase).

Voluntary Participation

Participation in this study was voluntary (Babbie & Mouton, 2006; Smith, Flowers, & Larkin, 2009). Therefore, participation was free from any coercion, and participants were free



to withdraw from the research at any time during the interview phase, analysis phase, and prepublishing phase (Smith, Flowers, & Larkin, 2009; Whitley, 2002). Receiving fertility treatment at SBAH was not dependent in any way whatsoever on participating in this research project and was made clear to the potential participants.

Participant Privacy

Participants' identities remained anonymous. The participants' responses were identified by pseudonyms within an interview (e.g. Interview 1: Jenny and Bob). A master identification file was created that linked interview numbers to names to permit correction of missing or contradictory information. This file will only be available for legitimate reasons (Babbie & Mouton, 2006; Langdridge, 2007; Whitley, 2002).

Informed Consent

Participants were invited to participate in the project and given information regarding the project in our initial meeting. All questions relating to the project were answered by me and thereafter, the couple made an informed decision, based on all information presented to them, whether they would like to participate in the project. The research participants provided written informed consent in order to show their willingness to participate in the research project. They received a detailed "Information Letter" stating the research content and process.

Psychological Support

Participants were informed that should they at any time feel overwhelmed by the emotions that were invoked by the interviews, they could talk to me and I would arrange psychological support services to assist them. Prior to commencing the study, I engaged with a colleague who agreed to work with any participant who felt they needed counselling as a result of the research interviews. These consultations would be provided for on a pro bono basis by the said psychologist (Appendix F). None of the research participants expressed a need for counselling services.

Material Storage

The material will be stored for 15 years at the UP Department of Psychology, in accordance with the requirements of the Department of Psychology.



Conclusion

This chapter serves as a floor plan of the research project, which required more flexibility than initially anticipated. The methodology was not always hard-and-fast, but gave key guidelines to follow in order to execute research that was consistent with the methodological principles of an IPA research project. As I examined the research process, I came across a familiar Frederic Nietzsche quote on the internet: "You have your way. I have my way. As for the right way, the correct way, and the only way, it does not exist" (Nietzsche, 1883/1978). When applied here, I thought of my journey as a researcher with "all of my ways" that delved into the IPAway. This reminded me that there is no right, correct, and only way of conducting research, merely different ways, with different outcomes. The pinnacle of this study for me was sharing with you the lived experiences of South African couples who spoke to me about their experience of involuntary childlessness and with that, the treatment processes they embarked on.



PART D



REFLECTIONS

Introduction

I am a great lover of music, both lyrically and melodically. Although I have not taken up an instrument yet, my appreciation for the inherent beauty of music has been there for as long as I can remember. My ear has allowed me to connect with the poetry in the lyric that resonates with me, and from there it becomes a visibly embodied experience. I am as much a dancer as I am a musician, but the experience for me is liberating, euphoric and expressive. I am especially attracted to the growls of electric guitar, that in tandem with the vocalist communicate the intensity of emotion in a way that makes physical sense to me. Akin to experiencing music, has been this research process. Unsure of how the lyric may look as I began to analyse the data, the individual voices seemed like isolated notes at first, until much later in the analysis process when I began to move beyond "case to case" analysis and started the process of identifying common notes that began to string together their melody. Surrendering to the unfolding and development of emergent themes was a process that taught me many valuable things; one of which was that "the data is there, trust it to speak". In working closely with the data, I came to appreciate, question, and accept that the data may have spoken to me in specific ways and may speak differently to each reader hereafter. I further recognised that despite my attempts at portraying the authors' accounts as accurately as I possibly could, each author may have additional insights. This leads me to the importance of reflection throughout this process.

The one thing that has remained constant in this process is an unequivocal reflective process. Reflection as an important aspect of formal practice became an amplified component of my psychology masters training, where I felt a sense of congruence when introduced to the concept of reflective practice in both the therapeutic and research contexts. I have always engaged in a self-reflective practice of questioning: myself, my thoughts, and my feelings as they arise in context. Do I always get immediate answers? No. I do, however, recognise that I have checked in with myself and asked myself how it is that "something" was happening in an attempt to understand that "something" and my reactions to that "something", a little better. So, here I find myself doing that exact same thing when considering the interviews and how they unfolded.



On my foreground, and consistent with the epistemological position of IPA, is the attention given to reflexivity as it applies to quality in qualitative research and the attention drawn to the role of the researcher. The tandem connection between reflexivity and this research project lead me to consider closely the impact interpersonal interactions between the participants and I may have shaped the telling of their accounts of experience and the nature of the analysis. Smith, Flowers, and Larkin (2009) describe how people pay attention to, and reflect on, their own perceptions of the stories that people share with them. Reflexivity as it applies here, reminds me of one of Yardley's (2000) four principals for assessing the quality of qualitative research: sensitivity to context. Here Yardley (2000) draws attention to how sensitivity to context can be established in a number of ways; one of which is through the examination of the interactional nature of data collection within the interview context. Obtaining good quality data in IPA requires "close awareness of the interview process showing empathy, putting the participant at ease, recognising interactional difficulties, and negotiating power play where research expert may meet experiential expert" (Smith, Flowers & Larkin, 2009, p. 180). Consistent with this principle, I give an account of my interactional experiences with each couple, and how these unfolded throughout the research process. I believe the relationship between us not only influenced the accounts they gave, but also the analysis process. I share with the reader how the research plan as stipulated in Chapter 4 took some unanticipated twists and turns, which impacted not only my data collection, but also left me with some difficult decisions to make during the research phase of the project and with that, left me with questions later regarding how to approach the reporting of the data. After walking you through how the plot of the story changed, I then move on to introducing the master and superordinate themes that were identified, and conclude with how I decided to report on them in the end

The Interviews: What I Planned Is Not Entirely What Happened

I remember being asked by my friends and family "so, how is your research going?" This was a question put to me at different phases of the research process. Depending on where I was pragmatically, emotionally, and intellectually in the process, it evoked different responses in me. In particular, when I was asked that very question during the data collection phase, I felt uncertain as I faced what turned out to be an unpredictable interview process. As the eight months unfolded, I faced a research process that was unfolding quite differently from what I had initially planned (see Chapter 4). As I take an imaginary trip back in time to the data collection phase and from that point forward, I picture how I would have, in retrospect,



answered the quintessential question asked of me so often (i.e. "So, how is your research going?"). Quite simply, by showing the enquirer the image below:

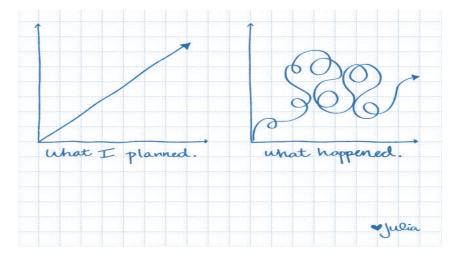


Figure 7: An illustration of the planning expectation versus the planning reality (Gamolina, n.d.).

In a nutshell, the image above sums up the trajectory of this research process. My research plan, which complied with the ethical and academic guidelines as set out by the Department of Psychology of the Faculty of Humanities at the UP, and Faculty of Health Sciences at the SBAH, was just that in the end – a plan. As the research phases continued, I was confronted with a series of experiences that I needed to make sense of and from there, make decisions on. In particular, during the interviewing process, what I did not "plan" for was that some couples would terminate treatment, and by implication, fall out of the research project. Although I knew that this was a possibility, I did not really anticipate it happening (possibly due to naive PhD excitement, as well as the naivety that came with being a novice researcher). I also did not consider the research implications of participants discontinuing treatment. Although the approved research plan contained sampling criteria for this project (please refer to p. 110 in Chapter 4 under the heading "Sampling Criteria") where I explained that the first eight couples who met the inclusion criteria for the project, and who agreed to participate in the project, would be selected, I did not stipulate a plan of what I would do should a couple fall out of the project. Therein lay one of the dilemmas I was faced with. What could I and should I do if a couple discontinued treatment and, therefore, fell out of my study? Do I pick up another couple to fill their place? Would this be appropriate? Would this be ethically allowed as I did not stipulate this in the research proposal? To what extent would I be manipulating the findings of this research project should I continue to take on new couples to fill the void of those who



left the study? These were only a few of the issues I considered when making my decision during the process. I provide the reader with answers to the aforementioned questions following a discussion on the couples who participated in this study, detailing our interactions and at what point they discontinued their treatment (if they did).

Ashton and Kerry-Lee (Couple A): Initiation

My experiences of this couple were comparable to my Grade 8 initiation into high school. It was exciting, overwhelming, nerve-wracking and filled with anticipation. I kicked off the data collection by interviewing this couple, and I distinctly remember driving to the REU at 6 am on a Monday morning feeling exceptionally nervous, excited, and at the same time a tremendous sense of accountability for capturing this couple's experiences. I remember feeling a sense of seriousness and that this seemed "bigger than me" where I needed to embrace my new role as "researcher" (whatever that may have meant). I journaled in the parking area that morning, noting that I did not want this couple to feel that their story was just "a means to a research ends" for me, but that their experiences were important inside and outside of the research context. Upon meeting the couple, I could tell that I was not the only nervous one as the interview process had a quick tempo in the beginning. Both the participants spoke quickly and so did I. The quick pace was not something I was very used to as my client interactions generally have a steady tempo. I quickly learned to catch up with the "work speed" of the interview, but admittedly probably missed a lot of reflective opportunities along the way. What struck me about this couple was their willingness to share, in detail, their experiences with me, despite a very religious Muslim background, which they themselves reflected on as inhibiting their sharing with others. I was humbled by their generosity, as they had not shared their active engagement in fertility treatment-seeking with community members, friends or even close family relatives. Reasons they gave for keeping their fertility treatment between themselves was the perceived religious and societal ramifications it could possibly have. I reassured the couple that their anonymity would be maintained and concluded the latter part of our initial conversation by reassuring them that no identifiable information would be disclosed in the attempt to help them feel more at ease in providing their account of experiences. I had the pleasure of a second interview with this couple, which was a lot more relaxed and conversational. Thereafter, the couple informed me that they were discontinuing treatment and moving to another province to "get away from things". A year later they informed me through personal messaging that they had fallen pregnant and would still like to read this research report once completed. I interpreted this as expressing their curiosity as to how their story read and



an inquisitiveness regarding other couples' experiences of fertility treatment. I chose to give voice to this couple's experiences by including their contributions in the findings, even though they discontinued treatment after their second treatment cycle. This is a research finding, after all.

Zethu and Bernard (Couple B): Intense Triad

The interview between Zethu, Bernard, and myself was nothing short of intense, hitting an unexpected crescendo relatively early in the initial interview. Following Zethu's disclosure that Bernard had been diagnosed with a condition known as azoospermia, she shared with me that all African cultures value bearing children and that she experienced ridicule, discrimination, and prejudice due to the couple's involuntary childlessness. She noted that the judgement began within the family, from her mother-in-law and sister-in-law and extended to the greater community. She shared that the community and family cited the reason for their childlessness as being due to a problem with her, where she had painfully experienced name calling as a result. Noted in the interview was the irony of this as she had no existing fertility issues, and was able to bear children. The paradox was such that she, in support of her husband, had kept the reason for their involuntary childlessness between them as a couple, but worried that should they utilise donor sperm to conceive, that her husband may exhibit issues when it came to bonding and attachment to the child and feared that there may even be incidences of abuse towards the child. At the point of disclosing these fears, Bernard elected to leave the interview. Ordinarily, in a therapeutic context I would have no problem in attempting to manage the conflict, and the strong emotions that lead to Bernard's exit, but now I was a researcher. I journaled the experience directly after that interview concluded, reflecting on that exact moment when Bernard left the interview: "Oh my goodness, am I a researcher in this moment or a therapist, or both?"; "How do I manage this situation so that I am not inhibiting a process but at the same time creating containment?"; "What is expected of me now?"; "What would my supervisor advise I do here?" I had no choice but to think on my feet. I listened attentively to Zethu as she emotionally shared her private experiences with me. We got to a place in that interview where I felt she expressed how she felt, was heard and contained, and at that point, I asked if I could then ask Bernard if he wished to join us again. He did, in body, but he did not share much thereafter. Upon reflecting back, I was not uncomfortable with the emotions expressed or the need for physical and emotional space that Bernard displayed. I was uncomfortable with not knowing the boundaries of my researcher and psychologist roles in the moment. I had to sink or swim, so I utilised both roles. Even though Zethu asked for a break



from treatment, citing financial costs of donor sperm and insemination as the reason, I felt that their experiences required an audience beyond me. So, I share their experiences in the two findings chapters.

Lesedi and Graeme (Couple C): Silent Partner

One of the standout experiences of this couple was the contrast between an openly communicative female partner and a very quiet and reserved male partner. I noted in my journal after interviewing all the couples that it was not uncommon for one of the partners to take the lead and be a little more talkative about their experiences than the other. However, in this instance, Graeme's silence in the interviews reflected his silence regarding the fertility treatment process in the couple's relationship. Lesedi shared with me that he did not talk about his experiences and would show his support by attending each appointment. Lesedi shared that she never really knew or understood the impact of the fertility treatment on him, and this was echoed in the research, as he sat silently. He would hold Lesedi's hand at times, put his hand on her leg or shoulder, but wouldn't say anything unless I prompted him by asking a question directed at him. His lack of communication, in the end, spoke. Another similarity that seems to be the golden thread with most couples interviewed, was their wish to keep their fertility treatment private. Of specific importance to this couple was that they asked for reassurance that I would not mention the name of the church they belonged to, for fear that their anonymity would be jeopardised. Their parents, friends, and extended community were not aware of their treatment seeking, and so, in my private reflections on this and other couple interviews, the deep sense of privilege I felt in being able to hear their stories and be trusted with such valuable experience, escapes adequate description. I was privileged to have had three interviews (the final one was attended by Lesedi only), following which they too decided to take a break from fertility treatment. Lesedi expressed that the treatment had taken a toll on her emotionally and she needed a few months to rest. Lesedi and Graeme's experiences were also shared in the findings chapters, despite their withdrawal from treatment following their third treatment cycle, for much the same reasons as I cited utilising the other participants' experiences: to keep their voices alive.

George and Mapuleng (Couple D): Distance from the Pain

I experienced a natural ebb and flow with this couple during the interview process. The conversation seemed to flow quite easily. However, awkward moments arose, specifically around how the couple met, the development of their relationship, and how their fertility



difficulties had an interpersonal impact. This couple shared that in their village of origin, it is customary to have five or more children beginning from the age of 18 years of age. Mapuleng described how people in their village would talk about them not having children, and the family would talk amongst themselves. In the Shona culture, it is not uncommon for a man to have multiple wives, sharing the pain of how a second wife may be able to provide a child for George. The pain of their infertility experience lead the couple to relocate to Johannesburg in an attempt to place physical and emotional distance between them and their community while they engaged in fertility treatment at the REU. The salient aspect of the interviews with this couple was how they both expressed a need to be away from home to provide distance from the pain of seeing children playing in the streets, mothers attending to their children, and people talking about and inquiring about their involuntary childlessness. Due to finances, the couple discontinued their fertility treatment and, therefore, their participation in this research project following my initial interview with them. Aspects of their story pertaining to the research question were told in Chapter 6 of the findings, ensuring that their experiences had the opportunity to be heard.

Keketso and Refiliwe (Couple E): A Story of Difficulty

I remember having discussions with this couple that often led to them deconstructing concepts and clarifying with me their intended meanings of words. It seemed very important, especially for Keketso, that I understood the difference between words utilised to narrate experience, and this importance was noted. An example was where Keketso was attempting to explain how, from a cultural perspective, he is viewed as accountable and responsible for the couple's infertility and his wife is perceived as responsible. Keketso described culture and tradition as having a symbiotic relationship. Culture, viewed as a broad concept for Keketso, was described as being in conflict with the practice of western medicine where his culture advocates the use of traditional healers. Herein lay part of their story of difficulty regarding their active engagement in fertility treatment-seeking and as head of the household, he has had some difficult decisions to make regarding their involuntary childlessness. The silhouette of difficulty extended into the couple relationship, which had already experienced periods of difficulty and now had fertility treatment to weather and the community ramifications that came with their childlessness. I found the interview process cognitively stimulating and enjoyed how the couple constructed their story in my presence. Their experiences are shared in the second findings chapter, although only one interview was had with this couple (albeit that it was a twohour interview). I contacted the couple to schedule a follow-up interview when I was told that



they were in a position of having to save money for treatment and did not know for how long they would need to suspend their treatment before they could continue.

Rozalia and Bongani (Couple F): Willing to be the Biggest Loser

As I contemplate this couple's process, I am blown away by their nine-year struggle with infertility and their resolve to keep going. After multiple visits with multiple traditional healers, the search for answers from medical doctors resulted in more of the same: a continued quest to get answers and fix the problem. Both partners have experienced societal ridicule, where they both reported being called names by members of their community. They also shared that prior to the family knowing there was a medical issue, the family also spoke about them to other family members, which they experienced as incredibly painful. Their infertility treatment has been shared with close family members only, continuing the golden thread of privacy regarding infertility and seeking treatment. One of the biggest challenges for this couple was for Rozalia to adhere to lifestyle advice given by their treating doctor at REU regarding weight loss. She was instructed to lose at least 18kgs in order to be eligible for fertility treatment as her BMI was not considered to be in a healthy range. When we began the interview process, she had lost 20kgs and described what an achievement that had been for her with the loving support of her husband. After she described the multiple challenges she faced in losing weight, such as they live in an informal settlement which is associated with poverty, coupled with the costs of purchasing healthy food and the costs of engaging in a healthy physical lifestyle by going to gym, I was humbled by the resolve of this couple to extend themselves to their limits in order to have a child. They too afforded me the opportunity of a lengthy interview following which Rozalia expressed requiring a few months to get finances together to pay for treatment. Their experiences are threaded throughout both findings chapters, although one may view their story as incomplete; like the other participants who fell out, it is captured here in the parts that I was able to access.

Lebogang and Sipho (Couple H): Marching On

This couple brought a sense of "business" to the interview process. The nature of the conversation was a little more formal and straight to the point. Perhaps the fact that both were soldiers in the South African Army may have shaped my view of the process in that the concise nature of this process seemed congruent with their military background. Both partners were able to discuss their experiences in a crisp manner, which seemed to adequately capture the couple's context and experiences of infertility in their military life. I was marched through their



experiences in such a way that nothing seemed overtly ambiguous in their narrations of experience, although admittedly there may have been missed opportunities as I recognise that my assumption of their conciseness may have inhibited me from opening up unexplored territory. Following our initial interview, the couple reported that they had fallen pregnant and no longer required treatment. That being said, their experiences are shared with the reader in both the findings chapters to preserve their experiences.

Logan and Mieke (Couple G): Against the Odds

I have left discussing this couple until last for a number of reasons, which I highlight at the end of my discussion of them. I am unsure of where to begin with this couple as I was moved in so many ways by the risks they took in sharing their experiences with me. Their story of nonconformity and the beauty that underscored it is something that still sits with me. Initially, they shared their story by illustrating how they met, and how they have been battling with infertility for four years. There were numerous accounts of seeking donor sperm and no tangible reason was given during the initial part of the first interview as to the need for donor sperm, until I asked the question. Logan's answer unexpectedly thickened their unconventional story. He shared that they were both biological females from an Afrikaans community where initially, their relationship was deemed as unacceptable and was given a label that did not sit well with either of them; that of being "lesbian". Logan described that he has completed the first of four phases in his gender reassignment process from a biological female to a male. Logan described himself as having a masculine identity and that this has been the case for his entire existence; he feels that while his mother was pregnant with him, female organs developed instead of male organs. The unfolding of their story throughout the gender reassignment process, parallel to their unequivocal wish to have their own child, was an emotional experience for them; a story that they allowed me to hear, despite Logan's repeated assertions that he only tells his story when he feels safe to do so. He could have answered the question regarding "why the need for donor sperm?" by merely stating there was a problem in producing his own sperm, but he told his personal story in such detail, allowing me to see how this had relevance, beyond the obvious, to their fertility treatment experiences. This process had to work, unlike his gender reassignment procedure that has not been an entirely successful one, and it did. It is a story of success against all odds and I am privileged to have witnessed the telling of their story. I chose to discuss this couple last as there was a lot to say about them due to the extensive time I was able to spend with them; so much so that I considered writing up the findings as a case study due to the sheer volume of research findings generated by their interviews. They provided me



with four lengthy interviews which yielded rich data on both IUI and IVF treatment experiences. Furthermore, they were the only couple who had completed an IVF protocol in my study and could report on those experiences in detail. Although I elected against solely utilising their experiences to answer the research question (although their experiences alone successfully did that) every participant's experiences that answered the research question, were included in the end. At times, especially in Chapter 6, a large proportion of the findings presented Logan and Mieke's experiences of fertility treatment, while findings from the other participants were presented to a lesser degree. This is purely guided by the richness of data obtained from Mieke and Logan. So, while Mieke and Logan's voices may seem rather amplified in Chapter 6, I wanted to keep the voices of the other participants alive.

As I look back at the couples, I feel an immense sense of privilege that they allowed me into what many of the participants considered to be a very private and intimate experience. With that, I feel and an immense sense of accountability to do justice to their experiences. The discussion on experience that follows in the subsequent findings chapters is what I consider to be the crescendo of the research project, providing insights into experiencing fertility treatment in the public health sector in South Africa. I begin with the identification of master themes, followed by a short discussion on how to understand the subsequent findings chapters.

Identification of Themes

IPA does not prescribe a single method of data analysis. However, one of the approaches recommended involves a line by line analysis of the interview transcripts, with the view of identifying emergent themes in each case and across cases (Smith et al. 2009). IPA of the semi-structured interviews was inductive, where units of meaning were extracted. The units of meaning were related to master and super-ordinate themes. This involved a hermeneutic process whereby the identified meaning units were informed by my reading of the literature on the topic. Specific attention was paid to the presentation of the findings which attempts to a) portray the participants' meanings as accurately as possible, and b) to present the extracts in an easy-to-read format. To achieve these outcomes, extracts from participants' interviews accompany each section to enhance the accuracy of the accounts provided, which is coupled with reflections on the interpretive process. Secondly, verbatim extracts are presented in a readable manner, where minor changes have been made to improve the readability of the extracts. For example, dotted lines may precede and follow an extract to indicate that the participant was talking prior to or after the extract. Furthermore, identifying information was substituted to assure the anonymity of participants.



Below is the table of master themes and superordinate themes identified that answer the research question:

Table 3:	Couples'	experiences o	f infertility treatn	nent in the public	health sector
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Master Themes	Super-ordinate Themes
CONTEXT Contexts shaping the participants' experiences of fertility treatment	• Private Healthcare Experiences
	Public Healthcare Experiences
<u>COUPLESHIP</u> The participants' coupleship experiences during fertility treatment	My Partner
	Shared Experiences

The table provides a global view of the themes identified, so that the reader understands how to position the salient experiences that will be addressed in each of the findings chapters.

The intention of the findings chapters is two-fold. Firstly, to provide a platform for the telling of the participants' fertility treatment experiences, and secondly, to present my interpretations of the authors' sense-making as it relates to the research question, whilst at the same time, remaining cognisant that the selected themes provide only one possible account of the participants' experiences. I am acutely aware of the possibilities of additional interpretations and insights that could be put forward as the results are read and re-read by others. Unlike a virtual space where one can comment in the comments section, there is no virtual platform for that here, but I do envisage what that may have looked like if it were possible. Perhaps one day in the future, academic documents will be more interactive.

In preparing to write up the findings of the research, I chose to attend to each Master Theme as an entity: The first represented in its own chapter (i.e. the contextual experiences that shaped participants' fertility treatment experiences are represented in Chapter 5) and the second and third Master Themes are presented in the chapter thereafter (Chapter 6) as those results refer to coupleship experiences during fertility treatment. The division of the findings into two separate chapters allowed me to extensively explore each Master Theme in relation to its corresponding Superordinate Themes. Table 1 on page 112 was provided as a working example of how one could understand how the two findings chapters, together and on their own, answer the research question.



Conclusion

In this section, which precedes Chapter 5, I shared with the reader how my initial research plan took some unanticipated twists and turns, impacting not only my data collection, but also the reporting of the findings. I shared with the reader my initial research plans and how these changed in tandem with the interview process. These changes required adjustment not only in my approach to the research process thereafter, but also an adjustment to how I perceived and worked with the findings of his research project thereafter. In the end, I decided to keep each couple's experiences alive by including them when their encounters helped answer the research question. Retaining their voices meant that some participants such as Mieke and Logan's voices are louder than others due to the volume of research data garnered. Following the discussion on how the plans changed, I then moved on to introducing the master and superordinate themes that were identified in the findings, and concluded with how I decided to report on them in the end by dedicating two chapters to the findings of this project.

I begin sharing the findings by first considering the interplay between contexts and fertility treatment experiences, followed by the subsequent chapter which reports on the interplay between fertility treatment and the couple relationship, concluding that chapter on the coping couple in treatment.



CHAPTER 5: FINDINGS

Contexts Shaping the Participants' Experiences of Fertility Treatment

...I was just guessing At numbers and figures Pulling the puzzles apart Questions of science Science and progress Do not speak as loud as my heart... Nobody said it was easy... No one ever said it would be so hard...

"The Scientist"

(Berryman, Buckland, Champion, & Martin, 2002, track 4).⁹

⁹ Lyrically, this song portrays a struggle. The difficult journey of identifying a problem and trying to find solutions resonated with me when I reflected on fertility treatment experiences. The intricacies of peoples' subjective experiences are encapsulated by the lyric "nobody said it was easy. No one ever said it would be so hard." The findings of my study speak to the "hard" parts as well as pleasantly surprising experiences.



Introduction

I have encountered great teachers, some of whom are in my past, while others, whether it is subtly or more overtly, continue to inspire me. As I reflect on who I choose as "teacher", I find that I am drawn to those who critically explore their world in marvellous, unique and sometimes unapologetic ways. Their curiosity resonates with me, magnetically holding me captive as we open up novel conversational spaces. This does not mean that I do not enjoy light-hearted banter, quite the contrary! But again, wittiness and clever quirkiness never fall on deaf ears with me. It is here that I fondly remember my beloved childhood author, Roald Dahl, who embodied all of the above and then some. Whilst I only got to experience him through the pages of his books, it was there that I had many internal conversations, and it was there that I learnt the importance of, and deep appreciation for, stories and storytelling. As I eagerly and effortlessly flipped from one page to the next, my mind was indulged by his often macabre use of humour as he gave me a guided tour of unimaginable worlds. As an adult, he really understood children, employing idiosyncratic humour as he drew you into the wonders of the worlds he invented and brought to life. It was all so off-centre. I really liked that! There were also so many colourful elements to his stories that surprised me. I really liked that too!

Having not too long ago read a biography detailing the colourful life of Roald Dahl, I marvelled at his entire story. O7ne element amongst many that stood out for me was the space in which his characters and stories were brought to life. Described as a little garden cottage, smoky and messy inside, was the magical place where the innovation happened (Sturrock, 2011). I am not sure what I was expecting, but it was not quite as rustic as that. I liked that even more! In a sense, I felt like I could understand his quirkiness even better where, much like a child's toy room, scruffy and chaotic as their imaginations are set free, so too was his, as I envisaged him messily embracing his childlike side as he penned the stories of marvellous characters, while all the while happily chain-smoking as he did it. The irony worked!

So, as I fondly remember Dahl's many lessons he taught me here, I reflect on how this shaped some of my research experiences. Dahl's attention to infinite details of experience brought to life the most unimaginable stories of magical characters, that, if he had left those details unattended, the story would have lacked lustre. How does this link to this research project? Quite simply, Dahl's attention to detail taught me the importance of the details themselves. He taught me that if I am to explore the details of others' experiences, I need to respectfully employ curiosity into the overt as well as the subtle aspects of those experiences,



all the while checking my assumptions. I have learnt that exploring other people's experiences with them is by invitation only, where a guided tour of their experiences may take some time, and may have some unanticipated twists and turns as their stories develop. I have applied all those lessons here, not only in the interviewing and data analysis, but also in the way I chose to write up this research report. On that note, I thought it appropriate to let Mr. Dahl introduce my research findings, utilising a quote from his last children's book: "And above all, watch with glittering eyes the whole world around you because the greatest secrets are always hidden in the most unlikely places. Those who don't believe in magic will never find it" (Dahl, 1991). What you will find as you navigate the results chapters, are experiences that were nestled in the most unlikely of places. Believing in "magic" is what helped me hear them in an unlikely place such as the REU.

I share with you now the experiences of the participants who allowed me into their fertility treatment world. The narration below represents my interpretation of the participants' interpretations of their experiences, written in a literary style as I hoped to retain the authors' voices as well as the integrity in which they were shared with me. This chapter introduces the reader to the contexts which shaped the participants' fertility treatment experiences. The context here, as with any story, anchors the participants' experiences as well as provides the reader with insight into their decision-making as they considered their fertility treatment options. I explore the participants' conflicts as well as the turning points they encountered in their treatment journeys and conclude this chapter by making sense of the various contextual elements that couples expressed were meaningful to their fertility treatment in both the private context and more importantly for this study, the public healthcare context. This chapter is to me like the introductory chapter of their stories. It not only sets the scene, but explains to the reader how the scene shaped their treatment experiences. The second findings chapter explores the participants more fully, giving the reader insight in to their coupleship experiences during fertility treatment. I begin sharing the participants' experiences of fertility treatment with the reader by exploring where it happened and how it mattered.

Context Matters

Amongst my many teachers were the participants of this study, who, as they shared their experiences with me, taught me about the diverse aspects that shaped their fertility treatment experiences. Participants introduced me to the milieu in which their treatment took place and how their experiences there influenced their decision-making later. Couples who had received



treatment in contexts outside the REU (such as the private healthcare context) sometimes described these experiences in contrast to their experiences of public healthcare fertility treatment. In this sense, the larger fertility treatment context was segmented into two settings in which treatment takes place in South Africa: the private healthcare context and the public healthcare context. Although my study focused on the experiences of couples who were undergoing fertility treatment at a public healthcare facility, the private healthcare context could not be ignored.

Those participants' who had accessed private healthcare, shared that it was (i) unaffordable and (ii) a disappointing experience overall. Contrary to private healthcare experiences, participants who were actively accessing fertility treatment at the REU at SBAH, shared that they encountered a more positive experience, especially when it came to service delivery. Couples expressed that they enjoyed (i) comprehensive, (ii) informative, (iii) conversational, and (iv) facilitative services at the REU. These findings were in direct contrast to the experiences of those participants who had accessed private fertility healthcare, even if their treatment there was brief or limited in scope. Below is an image which provides the reader with a global view of the contextual findings of my study:

CONTEXT					
IC HEALTHCARE EXPERIENCES • Comprehensive • Conversational • Informative • Facilitative					

Figure 8: A representation of the research findings as it relates to the context that shaped participants' fertility treatment experiences.

The figure above represents the participants' experiences of two different fertility treatment contexts. By allowing participants' contextual stories to be told (i.e. both private and public contexts), you, the reader, have the background story of the meandering paths taken by the participants of this study. I begin with participants' private healthcare fertility treatment experiences.



Private Healthcare Context

Three couples in my study began fertility investigations and/or treatment in the private sector before exploring treatment opportunities in the public health sector. Their experiences provided both insights into their experiences of private healthcare fertility treatment, which helped me understand their public fertility treatment experiences better, and also provided a rationale for their choice in opting for public healthcare treatment later. It was for these reasons I chose to include these findings here.

I begin their story in this chapter, by exploring the first of two salient aspects that underpinned participants' private healthcare fertility treatment experience: the high costs of private fertility treatment. From there, I guide the reader through a discussion of the disappointment participants experienced when accessing private fertility treatment.

No Financial Buffering: An Unaffordable Treatment Option

With this project being set in the South African landscape, I was prepared for the likelihood that affordability of treatment in some or other form would be an important aspect of fertility treatment experiences for the participants of this study. I suppose the literature, in part, informed my assumptions but by being aware of the financial position of the participants prepared me for the possibility that finances would be an important element of fertility treatment for these couples. And it was. Participants of this study vividly portrayed a precarious relationship between wanting a child on the one hand, and not having the financial capacity to afford accessing fertility treatment on the other hand. Negotiating this relationship was difficult for each of the participants, none of whom were in a financial position to freely pay for treatment. The more I worked with the research data, the more I realised that the issue of affordability was an important facet of participants' treatment experiences for two reasons. The first being that it provided me with insight into one of the driving factors that lead couples to seek public health sector treatment in the first place (i.e. their decision was financially motivated as it was a more affordable option). The second realisation was that for the three couples who accessed private support first, their private treatment was short-lived as it was not a financially sustainable option.

Participants who had accessed private healthcare treatment first, expressed that there were no financial support structures in place to buffer the monetary demand that came with treatment. Treatment was unaffordable due to (i) medical aid limitations and (ii) the absence



of personal accounts which would have assisted couples to manage the costs of private treatment over time. The expense of private fertility treatment became a significant deciding factor for couples, when considering accessing a treatment provider. I begin with medical aid limitations, highlighting how this shaped the participants' experiences of fertility treatment in the public healthcare context.

Medical aid limitations. Of the eight couples who participated in this study, only one had medical aid. This implies that the other couples found themselves in a position where, should they require any type of healthcare for whatsoever reason, they needed to pay for it out of their own pockets, or, access public healthcare treatment. The couple in my study that did have medical aid and considered utilising it to pursue private fertility treatment, discovered that fertility treatment was unfortunately an exclusion from their medical aid coverage, and private fertility treatment, therefore, became an unviable option for Lesedi and Graeme.

Lesedi, in explaining the couple's process of evaluating their treatment options, identified how their decision was weighted against the associated expenses of treatment. Sharing the lengths, she went to in her pursuit to access treatment, Lesedi explained that "I went to my employer "although "my medical aid wasn't financed by my employer." She explains her decision to ask her employer for help stating that, "I asked them 'do you cover something like this?' and they said 'no, we cover the consultation, but the treatment, the medication, and the procedure we don't'. "Lesedi explained how important the additional support would have been "since my husband is not working I could not afford to go to a private institution." One of the findings of this study was the couples' desire for privacy during treatment, which I address in Chapter 6). Lesedi's disclosure to her employer seemed motivated by three facets: the first was the couple's medical aid failing to shoulder some of the fertility treatment costs. The second was the expense of fertility treatment in general, and the third was due to her husband being unemployed, which was an additional financial stressor. All of which made private fertility treatment an unaffordable option for this couple. Seeking assistance from her employer meant that the privacy the couple maintained up until that point was wavered in the hopes of receiving assistance to initiate private fertility treatment. To me, this said a lot about their desire to have children, and the lengths that couples will go to to actualise their desire for parenthood. Although her employer was unable to assist with treatment costs, Lesedi shared with me that she "started searching to see if there were public institutions that offered such services and these people came out. Thank God to Google, because then I saw it, and then I started calling."



Although private fertility treatment was an inaccessible option for this couple, this did not stop their quest for a more affordable option, which they discovered was available at the REU at SBAH.

In addition to medical aid limitations hindering couples from accessing private healthcare, couples' experiences of fertility treatment in the private healthcare context were also shaped by the absence of personal accounts.

Absence of personal accounts. Medical aid limitations were not the only obstacles experienced when it came to accessing private fertility treatment. Another financial barrier that shaped couples' experiences of fertility treatment in the private healthcare context was the absence of hospital accounts, which may have made it more manageable in the short term for couples to access private treatment.

Logan shared that the absence of personal accounts meant that they could not pay off treatment, which prevented them from fully accessing treatment in the private sector as they were not in a financial position to do so. Mieke's request for a second opinion at a private healthcare facility was considered against the mounting treatment costs they had already acquired at the REU, and with that, the resultant conflict that this request introduced into their relationship. Logan shared that "I had a fight with her because she said to me 'I'm not going back again now after the last one, I'm not going back, we will go for a second opinion'. "In response, Logan asked Mieke if she knew "what it costs to go private? I mean we've got an account here that needs to be settled, and now to start a new one with a private hospital where they don't have accounts. You need to pay beforehand. "The absence of personal accounts prevented this couple from accessing fertility treatment in the private healthcare context, as they simply could not afford to pay for treatment upfront. The conflict seemed two-fold to me: on the one hand, the dilemma of not being able to have a gradated or manageable way to pay for private treatment created intrapersonal conflict on the one hand for Logan as this posed an obstacle to accessing any additional treatment, and on the other hand, it created interpersonal conflict in the partner relationship as they were already in a position of having to pay off an account at the REU. Here, Mieke wished to access another opinion, but given their current account at the REU they could not afford additional treatment costs elsewhere, which was a source of conflict for the couple. To me, the conflicted position of this couple is highlighted by the very irony that is inherent in an "account system." Accounts assist people to pay off



purchases which they otherwise could not afford once-off, therefore assisting them to purchase what they desire. However, having to pay the account off can financially imprison them, preventing them from accessing other services until their current debts are paid.

As I reflect on participants' experiences of private fertility treatment as an unaffordable option, the salient aspects that seem to shape their experiences, and that are common to both couples mentioned above, is the lack of personal finances needed to pay for private treatment. In other words, both couples required financial aid either through medical aid to shoulder the treatment costs, or in the form of an account system to buffer the costs. In the end, the absences of both lead to private fertility treatment being a dead-end option. For those who did try private healthcare treatment initially, aspects other than finances also shaped their fertility treatment experiences.

In addition to the high costs of treatment representing an obstacle to accessing or continuing private healthcare treatment, participants also shared that their private fertility treatment experiences were shaped by disappointment.

A Disappointing Option

Two participants, in narrating their experiences of fertility treatment at the REU, comparatively drew on their private treatment experiences. This not only gave voice to what they were dissatisfied with in the private sector, but also illuminated what drew them to public healthcare treatment. Upon sharing their private healthcare experiences with me, both couples shared their experiences of disappointment in private healthcare fertility treatment. Couples' shared that their disappointment in private healthcare treatment lay in the (i) patient care they received and, for the couple who endeavoured to access private treatment on a shoe-string budget, they quickly realised that private sperm bank options, for example, while more affordable, it disappointingly fell short on (ii) the scope of services they could offer.

The discussion on disappointment begins with participants' experiences of poor patient care in the private sector, followed by their experiences of disappointment in more affordable fertility treatment options that they explored.

Patient care. One participant vividly sketched his disappointment with the patient care they received as a couple during their fertility investigations. Ashton specifically highlighted



how the couple's fertility treatment experiences were shaped by their disappointment in the (i) vague feedback they received, and their overall experience of private treatment being (ii) poor value for money.

Ashton was disappointed with the vague feedback the couple received following a failed treatment cycle, sharing that, "the last time it didn't work, and we weren't getting proper feedback from the gynae that we were seeing in Jo'burg." His disappointment extended further where he experienced private treatment as poor value for money, explaining that, "you pay R1400 per consultation there and then they just do a sonar and say 'okay that's it, bye bye'." As he shared their experiences of disappointment, Ashton comparatively highlighted their experience of poor patient care in the private context, against the value for money experience of treatment received at the REU, saying that "here at least they do real checks and they tell you exactly what is wrong. Here you get good treatment". It seems that Ashton felt the couple received "good" patient care at the REU, which he saw as comprising thorough examinations and provision of clear feedback to patients; this compared to disappointing patient care, at high costs in the private sector.

Other than experiencing disappointing patient care in the private sector, the more affordable private treatment alternatives were also fraught with disappointment.

The low-cost option. Participants' experiences of disappointment did not only rest on patient care, but also extended to the type of private healthcare accessed. Logan and Mieke expressed their disappointment with a more affordable private healthcare alternative: a spermbank-only treatment option.

Logan and Mieke, in echoing Ashton's experience of private fertility treatment as an expensive option, engaged a private sperm bank facility in a "do it yourself" attempt at solving their fertility difficulties, whilst at the same time, trying to keep expenses to a minimum. Logan shared that "we went to the sperm bank to do it ourselves because it was too expensive to go to a private company or hospital. "In explaining the reason for beginning treatment at the sperm bank, he discussed that alongside his inability to produce sperm as a transgender male, he *further "never knew about Steve Biko Hospital.* "The couple's attempt to access private fertility treatment on a limited budget was initiated because the couple was unaware of a less expensive public treatment option offered at the REU.



For Mieke and Logan, it seems their experiences of sperm-bank-only assistance was marked by disappointment, aligning with the adage that "cheaper is not always better". Logan shared that the couples' disappointment lay in the limited scope of treatment offered at the sperm bank, explaining that "at the sperm bank it's not a fertility specialist, you get the sperm and they just inseminate. They don't do the medication, that's it." The less expensive private treatment option was experienced as limited in scope as the couple got what they paid for (i.e. they paid for sperm and that is exactly what they were provided). To me, it seemed that although they were aware that the sperm bank specialised only in providing sperm, there was a sense of disappointment that they did not extend their services beyond that. The couple's experiences of sperm-bank-only treatment as being limited in scope was not only experienced as disappointing, but raised concerns for them regarding the professionalism of the services offered. Upon reflecting on her personal experiences, Mieke shared that, "if I think about it, it was unprofessional because I can have cysts, and now you are taking my money, and you don't even know what's going on with me." Logan agreed with Mieke's perception of the sperm bank offering unprofessional services, as he questioned the staff's medical knowledge and expertise in performing inseminations. He shared with me that, "you can buy it directly from them, and then they do give you the option to inseminate it, but I mean it's the same guy that's sitting there at the back looking at the sperm checking the fertility, and he doesn't have a clue." It seems that this couple's experience of sperm-bank-only treatment was disappointing as they questioned the professionalism of the very service they were accessing. In this vein, it seemed that they wondered how ethical it may be to offer sperm to people when the health of the patient is unknown and secondly, they questioned the expertise of the personnel when insemination became an option (i.e. are the people inseminating qualified to provide this as a service?).

Whilst the views and experiences of the participants in this study are not intended to be generalised to the South African population, since they represent only a small sample, it does give healthcare professionals such as myself some insight into the aspects of treatment on which couples may place importance. For example, I underestimated the importance couples may place on the scope of practice offered by service providers, as well as their assessment of professionalism and ethical conduct whilst undergoing fertility treatment. I was surprised that Mieke and Logan experienced a sperm-bank-only treatment as disappointing. Surprised, because I thought perhaps their disappointment may have centred on the cost component of private fertility treatment and the barrier this may have presented in continuing private treatment. However, their disappointment lay in the limited nature of services offered and



whether such a service should be offered to the public in the first place in the absence of a detailed fertility investigation. Their critique of a sperm-bank-only option made me more cognisant of the breadth of contextually meaningful experiences of couples undergoing fertility treatment and the evaluative aspect of those experiences.

Keeping participants' experiences of private fertility treatment as an unaffordable and disappointing option in mind, I now explore the detailed and intricate kaleidoscope of participants' accounts of public healthcare fertility treatment. Their experiences not only surprised me, but altered my own perceptions of public healthcare in general.

Public Healthcare Context

Although a "make or break" facet of fertility treatment can quite obviously rest on affordability, participants' public healthcare treatment experiences extended beyond Rands and cents for the couples in this study. Participants identified experiencing a breadth of fertility treatment services at the REU. I share the next part of the discussion with you by first exploring couples' experiences of comprehensive services offered at the REU, before addressing other fertility treatment service experiences.

Comprehensive Service Experiences

Although participants expressed experiencing fertility treatment at the REU as a comprehensive service through the staff's professional conduct and their willingness to engage consultant opinions when necessary, participants shared that this was not their initial impression of fertility treatment in the public healthcare context.

Preconceived perceptions. Participants shared that prior to engaging in fertility treatment at the REU, they questioned whether fertility treatment in the public healthcare context would be of a poor standard. Logan highlights this perception when he shared with me that, "when I went to Steve Biko Hospital, I mean it's a government hospital, and you are not used to that type of treatment when you go to a government hospital." Logan explained how his partner shared the same initial perception of public hospitals as providing poor quality treatment in saying that, "when I told her we are going to Steve Biko she was like 'no way', but I said, 'you know, let's just try''and "when we went there, and we met our doctor, it was amazing." It seemed that the participants' engagement with fertility treatment at the REU challenged and created a shift in their perception of public healthcare treatment.



What seemed to specifically challenge the participants' perception of public healthcare fertility treatment was the aspect of professional conduct.

Professional conduct. The first aspect of treatment that challenged participants' perceptions regarding public healthcare fertility treatment was the aspect of professional conduct. A participant expressed that the professional conduct of the staff at the REU was an important facet of the comprehensive service she experienced there. Kerry-Lee, in comparing her treatment at the REU with an experience at another treatment facility, stated that, *"this is more in detail, like everything...the explanations and the procedures."* The comprehensiveness extended from the professional conduct in the detailed investigation to the professionalism in the explanations given regarding treatment.Another important aspect that challenged the participants' perception of public healthcare fertility treatment was the treating doctor's engagement with other consultant professionals to discuss couples' treatment.

Engaging consultant opinions. The second aspect that challenged the participants' perception regarding public healthcare fertility treatment was the aspect of consultant opinions. Participants experienced comprehensive treatment which was expressed through their doctor's engagement with consultant professionals regarding aspects of their treatment. Zethu provided me with an example of a time where their treating doctor demonstrated a drive to help the couple, as she expressed that, *"they did everything, they even called specialists, and even called many doctors, where sometimes there were four doctors in one room discussing the issue."* For this couple, their experiences of fertility treatment as a comprehensive service were shaped by their treating doctor's engagement with other professionals signifying that they "did everything they could" to assist the couple.Set against the good news backdrop of comprehensive treatment experiences, was one couple's disappointing experience of another public healthcare facility. There they experienced less than satisfactory treatment, which implies that not all public healthcare facilities provide the comprehensive services that the REU provides to its patients.

An alternative experience. Not all couples' initial experiences of public healthcare were savoury ones, with one couple sharing their disappointment in the service they received at another public healthcare facility, prior to becoming patients at the REU.

Lebogang and Sipho are soldiers in the South African Army, and initially began their fertility investigations at an alternative public healthcare facility. Although the facility did not



specialise in fertility treatment per se, the couple initially sought assistance there. Lebogang shared with me that, "sometimes we went there and we found that we had a gynaecologist student" and other times "we had to start with the file again and do some tests again." The couple expressed experiencing disappointment due to the lack of consistency in treatment. They understood the inconsistency in treatment as being directly influenced by not having one doctor appointed to their case, where student gynaecologists were appointed to manage the couple. This inevitably led to the repetition of tests and treatment. Sipho elaborated on Lebogang's experiences of poor quality service at the initial healthcare facility, saying that "it was different doctors every time we went there you see, there was not one doctor that you know..." for example, "when we came here, we see our doctor" but at the initial public treatment facility it was "different doctors and they all read the file, gave you advice, saying do some tests and then when you go again, they read the file." Sipho expressed that every time they went there "we were thinking we are going to get help but only to find out they don't check for a year. I can say it was not right." The couple's directionless treatment experience at an alternative public healthcare facility, due to multiple doctors handling their case and with that, the repetition of tests, ultimately led this couple to channel their dissatisfaction by shifting treatment gears and engaging in treatment at the REU.

An additional feature which was identified as significant to couples' treatment experiences at the REU, was their tandem experiences of a conversational service.

Conversational Service Experiences

A surprising finding from my study was that participants did not only express their satisfaction with the comprehensive medical treatment they experienced at the REU at the SBAH, but for some couples, the REU also provided a conversational service where couples could emotionally check in on their fertility treatment experiences. While many couples expressed experiencing diminished communication in the couple relationship while receiving fertility treatment (which is tackled later in Chapter 6), it shows up here as significant to their comprehensive treatment experience at the REU.

Lesedi eloquently captured the significance of the REU in providing a time and place for the couple to talk about their infertility experiences. She shared that, "the only time that we probably talk about it is when we come here" explaining that it is the couple's way to "try not to focus too much of our attention on it and we try to go on with our lives" to try and live their



typical lives outside of treatment. She shared with me that "the next time when we come here, we deal with that situation as and when it happens." Reserving infertility experiences and treatment-related talk for the REU was a way for Lesedi and Graeme to compartmentalise their experiences within the boundaries of the REU, trying to keep other facets of their lives unaffected. This can have implications when considering a holistic treatment approach for couples engaging in fertility treatment, especially as it applies to supporting couples emotionally, which I address in the recommendations section of the last chapter. Other than the conversational service provided at the REU, participants' experiences of fertility treatment in the public healthcare context were also shaped by the experience of treatment as an informative service.

Informative Service Experiences

In addition to experiencing comprehensive and conversational services at the REU, participants shared that their fertility treatment experiences were shaped by informative services offered by the unit. Through being informed, it not only created participant understanding regarding the different elements of their fertility treatment, but also created treatment-related certainty. While some couples experienced being adequately informed, others felt that more could be done in providing information to patients.

I start the discussion by first attending to participants' experiences of how information sharing led to an understanding of their treatment process at the REU.

Creating participant understanding. Couples' experiences of fertility treatment as an informative service created understanding for participants in several ways. Through being informed, couples expressed understanding both (i) anatomical and (ii) procedural aspects of their treatment, as well as feeling a sense of (iii) empathic understanding from members of staff throughout the duration of their treatment.

Participants expressed that the provision of information created anatomical insight, clarity, and understanding. Ashton shared with me that their treating doctor "took out this book, opened it, and took us through all the pictures." Ashton explained how their doctor "showed us how it starts, how your follicles look, and showed us how this releases the egg, these are the tubes, and this is where the sperm flows through." Here, Ashton explains experiencing fertility treatment as an informative service at the REU when their treating doctor shared anatomical



information with the couple. This seemed to be an important aspect of their treatment experiences as he emphasised the anatomical clarity that unfolded as the doctor visually and verbally walked them through the anatomy involved when receiving fertility treatment. Couples' experiences of fertility treatment as an informative service not only created anatomical insight, but also a procedural understanding of their treatment process.

Participants expressed experiencing procedural understanding following the provision of treatment-related information from their treating doctor. Ashton explained how their doctor *"showed us everything, so you know what you gonna do and what to expect."* It seems that when procedural understanding was attained, participants gained a sense of predictability regarding their treatment process as it helped participants to anticipate what would be expected of them and what to expect regarding their treatment. Participants shared that in addition to procedurally understanding their fertility treatment better as information was shared with them, empathic understanding was also experienced through the informative services offered by the REU.

Couples expressed feeling emotionally understood and supported when their treating doctor attended to the emotional aspects of treatment. Ashton explained that the couple felt that while their treating doctor was imparting treatment information, she attended to the couple emotionally saying that, "they tell you if it doesn't work out, it's not the end of the world, they also help you emotionally through the process." This participant experienced the process of receiving information as extending beyond the anatomical and procedural treatment domains, where doctors normalised their concerns regarding the possibility of unsuccessful treatment outcomes. This gave the couple a sense of empathic understanding. Fertility treatment as an informative service not only created understanding for participants, it also created certainty regarding what to expect in their treatment process.

Creating participant certainty. Information seemed to be necessary for couples to prepare themselves for what to expect in their treatment process. The (i) creation of certainty through detailed explanations of what to expect regarding their fertility treatment was particularly important for couples at the beginning of their treatment. Whilst some couples experienced detailed explanations, others felt more could be done to (ii) enhance participant certainty.



Those who shared that they experienced fertility treatment as an informative service, highlighted the important role that their treating doctor and other personnel at the REU played in creating certainty through detailed explanations. Participants placed value on being given detailed treatment-related explanations from personnel at the REU. The more detailed explanations participants were given, the more this facilitated certainty for participants, which developed throughout the treatment process. Ashton, in highlighting the couple's initial experiences of disorientation on their first day of treatment, shared that, "we didn't know what the programme entailed" and explained how the process of clarity unfolded from the first day of treatment-seeking, where "on day one, when we got here, they gave us a brief, no not a brief, a more detailed explanation from day one." Ashton explained how certainty was created for the couple when the staff discussed "what we gonna do, when we gonna come the next time after that, what's the result from there, and then what's our next step". The first consultation was a particularly pertinent experience for this couple, as it was there that they received muchrequired information, which settled the uncertainty of the process for them. Ashton in sharing the couple's initial consultation experiences, explained that "basically on day one, they took us through the whole process of what's gonna happen until the day you fall pregnant or you not pregnant." Lebogang expressed the importance of their first consultation and their experience of uncertainty regarding their treatment process, but she was confident that they would be provided with information that would create the certainty and predictability that they were after. She shared that at first "we didn't have much of an idea, that's why we must wait for the sister. She's going to explain it to us and give us some pamphlets to read."

Although participants experienced an informative service at the REU, some couples felt that more could be done to enhance participant certainty during fertility treatment at the REU. Although Mieke and Logan concurred with the other participants that couples engaging in treatment require detailed information on their personal treatment protocols, unlike the others, they seemed to feel that more could be done. Logan, in speaking of their experience of their treating doctor said that she "always tried to give more information" but recognised that "it's not gonna be with every doctor here." Logan reflected on the couple's experience of nursing staff, who in fulfilling their daily tasks, may at times forget that couples are new to the treatment process. Logan shared their experiences with me explaining that "I think with the nurses, they do this every day, but to a new couple this is their first time and to them it's a big thing." He explained that couples new to the process have "never heard of IUI, they never heard of IVF, they never heard about injecting yourself that much a day" and as a result "I think the



sisters get annoyed with people." Logan shared how "I've seen it here with us, with everybody else, it's like they get annoyed because how many times do they have to say these things over and over, but I mean every couple you see it's their first time." These research findings highlight that although couples experienced informative treatment, which provided anatomical and procedural insight, as well as a sense of empathic understanding from their doctor and muchneeded treatment-related certainty, couples identified pockets in the information chain which could be enhanced in a continuous effort to improve service delivery. It comes as no surprise to me that information provision as a function of any service provider is in a constant process of improvement and development - "when we know better, we do better."

If I review my research findings so far, couples expressed experiencing fertility treatment as a multifaceted service offered by the REU at the SBAH. Participants did not only encounter comprehensive and informative services, but also shared that they engaged in meaningful treatment-related conversations with their treating doctor. In this regard, couples' fertility treatment experiences were shaped by the facilitative services they offered, which I turn to next.

Facilitative Service Experiences

I am acutely aware that up until this point, it may seem that of salient importance to couples engaging in treatment is the price tag, and the service delivery as it compares to that price tag. While these were important elements, they were not the sum total of participants' treatment-related experiences. So, with the "business" component out of the way, I can now address the other aspects of treatment that couples expressed as significance to their treatment experiences; one of which is the couple-doctor relationship.

For some readers, it may be an expected finding that couples value their relationship with their treating doctor. However, for others (myself included), the surprise was the intricacy of this pivotal relationship. My research showed that doctors not only have the responsibility of proficiently practising their well-oiled skills in the medical facilitation of treatment, but are also required to meet and deliver on patients' communicative expectations. Analysis of the findings highlighted that mutually open communication, stripped of its medical terminology, is encouraged, and in turn enabled couples to mobilise psychologically and pragmatically when it comes to treatment. Doctors are required to provide consultations that are psychologically mindful, empathic and supportive. They are responsible for creating a co-partnership with their



patients so that free will is exercised with the compliment of medically informed backing. I frame these as expectations because I believe that is what they are, encased in the experiences couples shared with me of their doctor-patient interactions. As they highlighted these as significant to their experience at the REU, it was a meaningful component to treatment for them and in saying that, seems part of their possible checklist when considering whether their experience of treatment was positive or not. When it came to this study, it was apparent to me that patients required a lot more than physiological treatment and for the most part, received just that.

An important facet of the couple-doctor relationship was the significance of their appointment time with their doctor. Consultations held immense value for couples, over and above the medical reason for bringing them there in the first place. Consultations were perceived as having interpersonal value for couples, allowing for (i) rapport building through personalised consultations. Couples experienced consultations as (ii) empathic interactions and as creating treatment-related (iii) opportunities in the treatment process. As with any communication, there can be (iv) unintended paradoxical interactions, which highlighted the importance of (v) communication during their consultation. Couples' experiences of the couple-doctor relationship as a facilitative facet of fertility treatment demonstrated that consultations are not a means-to-an-end for couples, but formed an important facilitative function in their treatment experience at the REU.

One of the aspects that shaped participants' experiences of fertility treatment were their encounters of personalised consultations at the REU which facilitated rapport building in the couple-doctor relationship. I explore this in closer detail next.

Creating rapport through personalised consultations. Couples expressed experiencing consultations as important to them, not just based on receiving sound medical treatment, but rested too on the importance of the couple-doctor relationship in its multitude of interpersonal and communicative intricacies. Couples expressed that their (i) doctor's patient-centred approach during consultations, as well as being assigned (ii) one doctor who (iii) provided their focused medical expertise, all contributed to the development of rapport in the couple-doctor relationship throughout their fertility treatment process. I discuss the first of the three aspects where a patient-centred approach during personalised consultations facilitated rapport for participants.



A patient-centred approach during consultations was significant to couples' treatment experiences, as it created a sense of warmth, and with that, rapport in the treatment process. Ashton shared the meaningfulness of his experiences of their doctor's approach, explaining that *"they are not only here as a patient and a doctor. They are like family. They are interested in you, and make sure everything goes well with your procedures. They come and talk to you."* The doctor's patient-centred approach created rapport in the couple-doctor relationship, where for this participant, the doctor's approach was more familial than clinical and as such, seemed more personal. Ashton highlights how their doctor's interactions resonated as family interactions would, where it felt like their doctor genuinely cared by taking an interest in them as a couple and speaking with them. Their doctor seemed to care about them and their treatment, which built rapport.

The development of rapport in the doctor-couple relationship seemed to be an important aspect for participants when considering what is communicated and what is withheld in those interactions. It is already inherently a vulnerable position for couples to be in when seeking treatment, but the vulnerability in sharing private information can have treatment implications and at the same time, possible psychological implications for couples. The feeling that the doctor-couple relationship is safe, encouraged the sharing of private information. When asked by their treating doctor during consultation why Logan could not produce a sperm sample, he described how he could openly share that he was going through gender reassignment. Logan illustrated his openness with his doctor as he described her as *"nice"*, explaining further that *"You can tell her anything and she doesn't even have a little bit of change in her face; it's just like 'oh okay', and then there's no judging at all.* "This patient-centred, non-judgemental approach created rapport between the couple and doctor, providing the context for transparency during treatment. Alongside the treating doctor's patient-centred approach, participants also highlighted that having one doctor assigned to managing the couple's fertility treatment further contributed to creating rapport.

Couples shared with me the meaningfulness of having one doctor assigned to manage their fertility treatment. Here couples identified that their treating doctor's familiarity with their case enabled their doctor to implement a streamlined treatment approach, which created a sense of predictability and certainty in the prescribed treatment, and further built rapport for couples within the couple-doctor relationship. Sipho, in explaining the importance of developing the couple-doctor relationship, highlighted how confidence grew throughout the treatment process,



sharing that, "she told us what is expected from us, and what we must expect from her. If you are using the same doctor, she knows where she started, and how long it took, and all those things." Lebogang echoed her partner's experiences by comparing their previous public facility treatment experiences and their experiences at the REU, where at the REU they were assigned one doctor to manage their treatment. In referring to their doctor, she expressed that"at least she knows what to talk about and what is the way forward for you guys, unlike every time we were seeing a different doctor. "Sipho elaborated on the sense of predictability that comes from being assigned one doctor, as the doctor "plots the way forward, saying 'okay, this is what is going to happen on this day, at this time" explaining that when they come for treatment at the REU they "know this doctor knows exactly where we are going, she doesn't just read the file and then just check who was writing here last time. "Having one doctor manage their fertility treatment created rapport through the doctor's familiarity with the couple's case, and with that, through the couple's familiarity with the doctor throughout their treatment. An additional advantage of having one doctor assigned to their case was that it gave participants the opportunity to experience and trust in their treating doctor's medical expertise, which also seemed to be an important aspect of building rapport.

Appointments have significant psychological meaning for couples. For the couples in this study, their treating doctor's opinion had authoritative value, and with that, the potential to create trust between the couple and doctor, which extended into the treatment process; a double-edged sword if we contemplate the implications of this. Doctors are undoubtedly in a position where they may be viewed as the expert, and the management of their expertise and the translation of this in the couple-doctor interactions require a delicate balance of medical skill and expertise, with an interactional finesse. Rozalia shared with me the importance she placed in trusting her treating doctor's opinion, as she explained that "*I said to myself 'you know what, I must listen to whatever the doctor is telling me*", highlighting that the doctor's opinion, and the difficulty that came with their expertise, saying that "*it's hard to deal with when you come to this type of a decision, and when you speak to, no, beg someone who is highly qualified*", explaining that "*a doctor tells you straight 'you know that you got a 50/50 chance', which is sometimes hard to swallow.*"

In my view, Keketso highlighted the precarious position fertility patients may find themselves in: Those who are undergoing fertility treatment are in a vulnerable position where



they so desperately want to have a child and seeking treatment may mean that the doctor may need to share things with them that they may grapple with. In other words, seeking help regarding conception difficulties comes at the risk of hearing how likely it is that they may conceive, which may be difficult to process for some. When it came to couples' experiences of their treating doctor as the expert, this inhibited some couples in vocalising their treatmentrelated questions.

Rozalia narrated how her view of their doctor as expert prevented her from exploring her uncertainty around the details of their treatment. Her inhibition, in turn, affected her understanding of what was happening in treatment, where she shared that "you don't know every procedure and what is happening. You just listen to them." Rozalia valued the treating doctor's expert opinion although it may have resulted in aimlessly following their directives. She shared how her view of their doctor as an expert, coupled with her fear of what she could be told by her doctor, silenced her when she had a treatment-related question, explaining to me that she was "scared to ask. I just want them to tell me. I'm scared to ask what is going to happen. I don't think I'm ready for that, when they tell me that for me it's enough." Rozalia's avoidance when it came to asking questions seemed two-fold: On the one hand, she seemed to follow the doctor's recommendations by virtue that the doctor was seen as the expert, so she did not ask questions. On the other hand, she avoided asking questions as she feared the outcome.

Alongside personalised consultations building rapport with participants, couples also shared that empathic interactions were an important facet of the couple-doctor relationship in their fertility treatment experiences.

Creating empathic consultations. It may be rather obvious that couples would experience empathy as an important aspect of their treatment experiences. However, I do believe that for patients, an empathic approach goes a long way in their doctor's communication and treatment development with their patients. Bearing in mind that patients are more than the sum of their physical parts can be valuable in plotting the treatment protocol with couples as they feel a sense that their doctor is invested in the outcome.

Logan shared with me that he experienced their treating doctor's expression of empathy as supportive, feeling that she was truly invested in the outcome. Logan shared that *"you can actually see the emotion. Every time we get bad news, she gets down, you can see it is true*



emotion. Not like I need to sympathise with them, but true emotion. "He shared that their doctor said "she so badly wants us just to get a positive result, that it feels like she's going through what we are going through. It's like it's her journey." Logan seemed to experience genuine empathy and support in their interactions with their doctor, where he felt that she was part of their treatment process, being equally as invested in the outcome as they were. Ashton concurred with Logan, highlighting the significance of empathy in their interactions with their treating doctor, sharing that "they not only here as a patient and a doctor. They are interested in you." Couples' experiences of an empathic couple-doctor relationship as a facilitative facet of fertility treatment, created the sense that their treating doctor had their best interests at heart and was invested in a positive treatment outcome.

An additional facilitative service that participants highlighted was the aspect of consultations as creating reproductive opportunities.

Creating opportunities during consultations. Couples expressed experiencing consultations as creating treatment related opportunities. Couples expressed that their consultations provided (i) hope and an opportunity to (ii) create direction through devising a treatment plan together with their doctor, and with that, experienced a sense of relief. However, the possibility of creating unintended paradoxical experiences during consultations was also encountered by participants, which I explore a little later. I begin with couples' experiences of consultations as representing opportunities for creating hope.

Participants expressed how consultations became more than a means-to-an-end. They were more than physical check-ups and treatment planning appointments. It was where they experienced the creation of hope. Rozalia explained to me the significance that consultations held for her when meeting with their treating doctor at the REU. Consultations were opportunities for creating hope, in comparison to the disappointment she experienced when accessing help from a traditional healer in the past. Rozalia shared with me that their treating doctor *"said to me 'no, you will get pregnant. I don't see anything wrong', it was like having that hope, having that hope, having that hope."* In the past, her family advised her to *"go to the Nyanga. You will drink the herbal tea, drink the herbal thing, and then you drink and drink and then nothing was happening."*Bongani concurred with his partner, explaining that although fertility treatment can be a slow and difficult process, their treating doctor provided his wife with reassurance and hope, saying that *"she talks a lot, giving advice, in fact, giving my wife*



hope, to say what we have to do. "Lesedi, against the backdrop of emotional pain and disappointment, described the hope that came with consulting their treating doctor, stating that "*this month we were starting to get a little bit excited because my periods were delayed by two days*", feeling positive about their imminent consultation, she explained that "*I was thinking 'this is it'. We both went and bought the pregnancy test and he looked at it, and there was just one stripe. Then I cried, but my hope was today.*" Although Lesedi experienced disappointment following the negative pregnancy test, she placed hope in the consultation the couple was having that day. Couples experienced consultations as opportunities for creating hope.

Combined with hope was the generative quality that consultations held for participants in that it was an opportunity for creating a treatment plan. Consultations provided an opportunity for couples, together with their doctors, to create a treatment plan, which created direction and in turn, a sense of relief. Logan described how their doctor's explanation of their treatment plan, provided not only a plan but also relief at the same time, stating that *"they said 'alright, we gonna do this, this, and this', and it makes you feel that, you know what, it takes that bit of stress off your shoulders."* Participants' experiences of having their doctor devise and explain their treatment plan, provided treatment-related direction and reduced treatmentrelated stress for couples. However, as with any interaction, there is the possibility of unintended paradoxical experiences.

Creating unintended paradoxical experiences. Some couples experienced consultations as hopeful opportunities, providing treatment-related direction, whereas, for others, consultations created unintended paradoxical experiences. At times, couples experienced consultations as (i) confusing, especially when medical terminology was used during their interactions, and expressed that some consultations were experienced as (ii) missed opportunities, leaving couples with gaps in their treatment-related understanding. Some participants also expressed that some (iii) consultations were experienced as stressful, as they confronted their infertility head-on. I begin with the first of the three unintended paradoxical consequences that participants experienced during some of their consultations at the REU: Confusion.

Couples required communication that was simple and that did not rely solely on medical terms. They required information that made sense to them, and for the most part, that meant simplifying the details. Logan, using the terms "medical" and "scientific" interchangeably,



demonstrated the importance of simplifying language to create treatment-related understanding. He discussed the importance of doctors explaining treatment-related details in a manner that was "not in medical terms, but is just normal talk, with normal words that you can understand. I think that will help a lot." As an illustration of how medical terminology can impede understanding, I utilise Logan's example of communication with his brother to illustrate the possible interactional difficulties that could unfold between the treating doctor and the couple in treatment. Logan shared with me how his brother was unable to understand fertility-related information and how this made it difficult for him to provide support to the couple during their fertility process. Logan shared the distantiating impact that medical terminology had on the relationship between the brothers, explain that "I asked him 'why did you never come and ask me and let me show you?' and he said, "'no, because you talk in scientific terms'." Logan explains that is "one thing that I would tell couples is to keep it in simple terms. Show them because then they can see it and leave the scientific words because they can't support you if they don't know." Medical terms were experienced as a barrier to understanding and in the interaction between Logan and his brother, a barrier to providing support. Medical terms also became cumbersome for couples attempting to make sense of their own treatment experiences. In accounting for her experience of treatment, Lesedi demonstrated this difficulty as she became tongue-tied, "I was very excited when they told us two eggs are at some stage where they hatched, and I don't know, I don't know the words."

Medical terms made it difficult for couples to articulate their own experiences of treatment and in Lesedi's case, she dropped the conversation there and moved on to another aspect of the experience. Whilst it is unreasonable to think that doctors, or in fact couples, will be able to utilise language that is completely devoid of medical terms, it is worth thinking about how we can make this more accessible and understandable for couples; not only to help them understand their fertility process better as it applies to treatment, but perhaps for them to be able to more easily make sense of their embodied experiences, and to share these experiences with others in a more relatable manner, should they wish to do so. Paradoxical consultation experiences extended beyond the boundaries of medical terminology where some participants walked out of consultations feeling that these were missed opportunities.

Participants shared experiencing certain consultations as missed opportunities, especially when it came to having their treatment-related questions answered. Here couples expressed times when they focused entirely on the physical pragmatics of treatment and forgot



to ask the questions that they intended to. Logan shared with me their experiences of consultations as missed opportunities, where he explained, "that's the main thing that every time we left here, we were like 'but we should have asked this, we should have asked that'." For Logan, consultations were missed opportunities when it came to asking pertinent questions. On the other hand, consultations were also experienced as stressful in that couples did not always know what to expect and did not know what to ask to gain clarity and certainty. Logan, in sharing his experience of the couple's first consultation, he described it as an event layered with unknowns and unfamiliarity, explaining that "you come in here for the first time and you have no idea what's gonna happen. So now you sit there and you don't even know what to ask, because what is there to ask? You never heard about IUI, so you don't know what's going to happen." The unfamiliarity of fertility treatment shaped Logan's experiences of consultations being missed opportunities at times, as their lack of knowing underpinned their failure to ask questions. Some couples experienced other unintentional paradoxical elements to fertility treatment procedures.

For some couples, consultations were experienced as stressful encounters. Some participants were acutely aware of what made consultations particularly stressful encounters, while for others, they were unsure. Rozalia shared experiencing appointment days as stressful, explaining that "every time when I come here it's like I'm nervous or something." She was unable to unpack and identify what it was that made it a stressful experience, saying only that "I don't know. I don't know...everything." It seemed that the treatment process was emotionally overwhelming in general for her. Logan, on the other hand, could isolate what made some of their consultation experiences particularly stressful for the couple. He explained to me that it was the manner in which their treating doctor conveyed information that amplified his experience of stress as it introduced a new stressor in the treatment process. He shared that their treating doctor "has a way of saying something that is now putting new stress on me, because when we walked away she said, 'now we just need to hope that they sit in the right place'."Logan shared how this then framed their subsequent consultation experiences as particularly stressful ones, explaining "that's why today I'm so stressed out to see if everything is where it should be because she said it, and now it's in my mind all the time."Attempting to make sense of his stress-experience further, Logan shared, "I think that's why I'm stressed because there is something in my head that is not fine yet, and I need to sort it out. "For Logan, his fertility treatment experiences in this regard were shaped by the unintended stress that



resulted from being provided information that he did not entirely understand. For the most part, it appears that participants required treatment-related information which seemed to emotionally contain them.

The importance of communication during consultations. Interactions during consultations are pivotal as an exchange of communication takes place between the parties. What should fertility-related communication ideally be like? I am not sure that there is a straightforward answer to that question. Are there unintended consequences of communication or the lack thereof? Yes, of course, as with most conversations, doubt, confusion, anxiety and uncertainty, as well as amplifying stress levels may be unintended consequences of communication (or in the absence of communication). As it applies to the experiences of treatment-related communication, this may inhibit psychological preparation for treatment. What came through strongly in my study was that couples required emotional containment through communication that was (i) open, which (ii) provided opportunities for bridging communication gaps and that was (iii) collaborative. I begin the next part of the discussion by focusing on the aspect of my research findings that showed that treating doctors assist in creating certainty through openly communicating with their patients.

Couples, for the most part, expressed experiencing open communication in their interactions with their treating doctors. Ashton shared with me the meaningfulness of having open communication with their treating doctor as it seemed to create a sense of predictability regarding their treatment process at the REU. Ashton shared that she "took me through all the details, showing us pictures, telling us stuff, what injections we will take and the injections we will be buying. If you are buying tablets, they will show you the box." Open communication was necessary for physical preparation. Logan expressed the pragmatic value of communication in creating certainty and predictability in their treatment process as "they give you your form and with it is what you gonna take. Your medication, when the cycle starts, the cost, and then you get this pack of paperwork." Logan's and Ashton's accounts of the open communication that the couples expressed experiencing gaps in information sharing, and how they experienced the emotional impact of these communication gaps.



Whilst communication can create clarity and relieve stress for couples, it can also create uncertainty and amplify anxiety. So, would less communication around the intricacies of treatment be better? My research shows that the lack of communication created doubt, confusion, anxiety, and uncertainty, which interfered with couples' ability to prepare for treatment. Although I explore couples' psychological experiences of fertility treatment more closely in Chapter 6, I briefly highlight here the emotional reactions couples experienced when communication gaps were experienced.

When participants were left to make sense of periods where limited communication was experienced during consultations and procedures, they experienced doubt in the outcomes of their treatment. One participant shared with me how she interpreted her treating doctor's silences and accompanying body language as meaning that things were not ideal. On her experience of embryo transfer, Lesedi shared that their treating doctor was "not finding the spot, but eventually, she did. They didn't give me that thing to say 'we did a great job.' Their faces didn't look appealing to me. I don't know, maybe they didn't want to disappoint me." It seemed that the lack of communication coupled with the non-verbal feedback created doubt for Lesedi regarding the success of her procedure, interpreting this as her doctor's way of shielding her from disappointment. This seemed to leave Lesedi doubtful of the outcomes of that procedure in particular. Aside from experiencing doubt, couples also expressed experiencing anxiety and stress when there were communication gaps.

Couples were left feeling anxious when there was a lack of communication and feedback. As I became more familiar with the REU, it seemed to me that there was a communication chain which took many forms, depending on the nature of the procedure. Nursing sisters, laboratory staff, doctors, and other involved personnel seem to have a system whereby information on embryo development, for example, is shared in a specific manner with the next in line, which ultimately ends in couples being provided with information on their embryo development. Policies that govern the sharing of confidential information are in place for numerous ethical reasons, and understandably so. Couples involved in fertility treatment may not always be aware of or understand how information is distributed, even when it comes to their own embryos, for example. Couples then may perceive the lack of forthcoming information as a breakdown in the communication chain, when in fact, it may be due to the REU's policies governing who is responsible for or allowed to provide confidential information regarding couples' fertility treatment outcomes.



Nevertheless, couples reported experiencing the lack of, or withholding of feedback as distressing. Logan describes the anxiety he experienced when he "phoned them on Thursday at 11:00 and I asked them 'can you tell us a bit about the eggs? How far are they?'" the sister replied that "they can't give out any information over the phone and the treating doctor is not in. So, we don't know, we don't know." Logan illustrated that their uncertainty was amplified by the lack of treatment-related communication. He shared with me that at the time they did not "know how many were left? How many took? How does it look? We don't know." He explained how the lack of information elicited several questions which centred on concern regarding the success of their embryo development. He went on to describe how their weekend was dominated by anxiety and uncertainty regarding their embryo development, sharing that, "I just don't want to come here and they say none of them made it. On Friday, it looked good, but anything can happen during the weekend." Mieke explained to me how the lack of communication created uncertainty regarding their treatment protocol and the rationale behind it. She shared that in asking treatment related questions "they don't give you answers." In explaining further, Mieke explained that their treating doctor, in response to her treatmentrelated questions, said that at the "next appointment I will tell you what's going on. The only thing I think they must change is the explaining." In exploring the usefulness and importance of explanations further, Mieke demonstrates how doctors should walk couples through their treatment, explaining that "you went for this, and we saw this, now we are going for this. So, I always don't know why." Sipho concurred with Logan and Mieke's experiences, where he shared with me the stress and confusion the lack of communication brought to their treatment experiences. He explained that "when we came here, we started everything afresh. It was a bit stressful because just imagine driving all the way to Pretoria then you come here, they tell you 'no, we don't want those things'" and then "when we come back again, they say 'we want these things.' So, it's a bit stressful sometimes, because they don't tell us everything." Some participants required treatment-related transparency and answers to their questions to contain their emotions and to prepare for what was to come in their treatment process.

For other participants, avoidance strategies were employed to manage the uncertainty of their treatment process, and the resultant emotions that were experienced. By not asking questions outside what their doctor had communicated, they continued the limited communication between the doctor and the couple. Rozalia illustrates the conflicted nature of communication, explaining that "*I don't want to know*. *I'm scared to ask because if I ask, I'm going to find disappointment there. I will wonder if I should never have asked that thing. It's*



like something bad that I'm going to hear." In this instance, Rozalia enabled the widening of their treatment-related communication gap. While Rozalia preferred a "not knowing" position in their fertility treatment, other couples independently created opportunities to bridge communication gaps, experiencing knowledge as a facilitative aspect to their fertility treatment.

I highlighted earlier in this chapter that couples were informed about the anatomical and treatment aspects of infertility at the REU, and in fact, considered the information as being more comprehensive than what they received in private treatment. I come back to it now as it is applied to their public health treatment experience in particular. For some couples, they felt the provision of information was adequate, whilst others felt the need to increase their knowledge through independent research. Some couples acquired additional information on their own to help bridge their gaps in understanding. Ashton acquired additional information, to create certainty around the administration of medication. To achieve this, he engaged with his treating doctor, but also verified information by conducting online research to create clarity. Ashton explains that "I just asked the doctor now, but I have been Googling about this IUI", finding out "what happens and stuff. I was just a bit curious about the timing after the trigger shot, so I was just making sure that it's not too late." Lesedi shared her concerns about having developed cysts which accumulated fluid during her IVF treatment, and her perceived idea of the negative implications it may have on treatment. She explains how she independently worked through these concerns through researching treatment options, "I Googled and found that this is not good. On the internet, they also said that if the doctor can aspirate it during the egg retrieval, it's a much better option." Participants independently supplemented information given to them by their treating doctor, with additional information obtained from the internet, which seemed to create a sense of predictability for the participants.

The internet provided an informative adjunct to the information that was provided in consultation. Logan explained to me that consultations were so comprehensive, covering so many bases, that it was not always possible for the couple to remember every detail because "you are so involved sitting and trying to listen to everything they saying and trying to take everything in that you don't remember when you get out here" explaining that he would "have to go back to Google to get the answer. "Logan highlighted "what helped me a lot was the photos on the internet, and reading about other people." For some couples, becoming knowledgeable about their fertility treatment was an important facet to understanding their fertility treatment. For



Logan and Mieke, being knowledgeable was imperative. Logan shared with me that "*I think the most important thing before you go on that journey is knowledge*", explaining further that "*knowledge is the best thing I think. That's your most powerful tool in this, is knowledge.*" Mieke explains the importance of knowledge sharing, acknowledging that she would feel immobilised without knowledge, "*if you didn't know everything I would just sit here like a zombie not knowing what's going on.*" In this instance, it seemed to me that Mieke experienced the acquisition of knowledge as a way of taking ownership of an aspect of their fertility treatment. In this sense, she could know more about their fertility treatment through research. Alongside strategies that couples employed to bridge communication gaps to improve treatment-related understanding, was the importance couples placed on collaborative communication in the couple-doctor relationship.

Couples placed importance on being able to collaboratively sketch out the treatment options with their doctor to exercise their free will in their treatment process. Lesedi discussed with me how she weighed up the couple's treatment options with their treating doctor who "didn't say much. She wanted to put me on some medication, where they say the sun is a problem. When I read the side effects I just felt I'm not ready for that, so I said no." Logan too, illustrated the importance of the doctor collaboratively discussing all facets of treatment with the couple so that they could make an informed treatment-related decision. Logan shared that their doctor "said we doing IVF. I said to her 'well either we'll do it with the right medication which I'm going to research. If not, then we will leave it. I'm not gonna waste the money'. "Couples' experiences of collaborative communication during the development of their treatment plan seemed to create a sense of ownership of their treatment and emotional containment to some extent.

If I survey my research findings on couples' facilitative service experiences, it was the couple-doctor relationship as a facilitative facet of fertility treatment which was valued highly by the participants of my study. It was there that (i) rapport was established and (ii) empathic interactions took place during their experiences of personalised consultations with their treating doctors. Couples experienced consultations as (iii) creating treatment-related opportunities, although, they experienced (iv) unintended paradoxical interactions with their treating doctor at times. This highlighted the importance of (v) communication during consultations with their treating treatment doctor throughout their fertility treatment journey.



Conclusion

What have I learnt so far regarding the findings of my study? Participants have taught me that their experiences of fertility treatment at the REU displayed a breadth of possibilities that I could never have imagined. Going into this, I had assumptions about what may have come up in the findings; many of which were informed by the pessimistic developing world literature I had read on fertility treatment, especially as it related to service delivery and finances. I could never have anticipated that in the most unlikely of places people shared experiencing such a wide range of services during such a painful time in their lives. Therein lay the magic. Here participants shared with me the fullness of their experiences of fertility treatment at the REU, citing that their experiences were shaped by (i) comprehensive, (ii) conversational, (iii) informative, and (iv) facilitative service encounters. Werethe services a shining example of perfection? No. But what I did hear is that they experienced more positive encounters than they did negative, and that is surprising considering previous literature. These experiences were just as surprising to me as the anomaly that is embodied by the Rubik's Cube itself.

As I move on to discussing the second instalment of the findings of this project, I wondered how I can explain to the reader how I personally conceptualised the findings and why I chose to discuss them in two parts. Possibly, the best way is to explain it like this: Chapter 5 addressed the contextual experiences of fertility treatment, whereas Chapter 6 focuses on people in context, so to speak, with particular reference to the self and to the couple system experiences of fertility treatment in particular. The separation of the findings chapters is by no means indicative of them being mutually exclusive. Rather, for pragmatic reasons, it enabled me to highlight the participants' salient experiences more clearly, allowing space for interpretation of findings. With that being said, I now move on to Chapter 6, where I explore fertility treatment experiences, before moving to couples' shared treatment experiences. The experience of the treated body within the couple system is explored and the discussion then concludes with couples' experiences of different systems whilst undergoing fertility treatment at the REU.



CHAPTER 6: FINDINGS

Couples' Shared Fertility Treatment Experiences

All of these lines across my face Tell you the story of who I am So many stories of where I've been And how I got to where I am But these stories don't mean anything When you've got no one to tell them to...

You see the smile that's on my mouth It's hiding the words that don't come out And all of my friends who think that I'm blessed They don't know my head is a mess No, they don't know who I really am And they don't know what I've been through like you do...

"The Story" (Carlile & Hanseroth, 2007, track 2).¹⁰

¹⁰ I deeply connected with the lyric as it speaks to subjective experience. Upon reflecting on the sharing of experiences, I am acutely aware of how graciously the couples invited me into their process, allowing me to experience with them, what was behind their smiles. As I considered the importance and significance of the participants sharing their experiences with each other and with me, I feel a great sense of privilege in sharing their experiences with others.



Introduction

Over the past 21 years that I have shared with my husband (17 years of which have been as a married couple) I have come to learn a few things, some of which are about myself, some about my partner, while other things are about "us" as we have evolved as people and in our relationship with one another. The learning is continuous, moulded by our experiences as individuals and the life that we share together. If I were asked what I consider to be my greatest triumph, it is simply: "my relationship with Judd." Having met when I was in my mid-teens and he in his second decade of life, by implication means that we have experienced a lot together, and we have. We have travelled together, not only parts of the world, but emotional terrain too. Singularly, one of the most impactful experiences that we walked together was our experiences with infertility. For us, for me, it brought tremendous heartache and levels of disappointment that I could never have anticipated. The feeling of despair at times was overwhelming and as Judd's partner, I felt like I failed him and our relationship hopelessly, as I was the one with the fertility issues. Judd's love and reassurance that it was an "us" issue conflicted with the messages my body was telling me as well as what our specialist shared with us about the problems we faced with our fertility (or the lack thereof). Having endometriosis, coupled with a thyroid issue, made me feel at times like I had an invisible disability where I carried defective organs that malfunctioned and, quite simply, were not doing what they were supposed to. So how could this on some level not be a "me" problem? I knew cognitively that this was rather illogical to blame myself and that as we continued our reproductive investigations, we learned more and therefore, could do more to "sort my body out", so to speak. My heart was another thing entirely. It wrestled with the hopeless disappointment of my body. It was one of the few times in my life that I can remember where, no matter how hard I worked at something, no matter what I did or did not do, I just could not fix this on my own. My husband, on the other hand, played such an active role throughout, for many reasons I suppose. Firstly, he wanted to be a dad. Secondly, this was happening to him too, and thirdly, it was happening to "us". His role in helping "fix" what I later was able to say was "our" problem, was bittersweet for both of us. After just under a year at the fertility clinic, IVF was recommended and Judd, equipped with the blue medicine bag given to us at the clinic, was given the task of administering the injections. Lucky for him I am a soldier when it comes to needles but by the second week, my stomach looked like I had used only my stomach as a shield in a paintball game or two. The last injection was the straw that broke the camel's back. I swore that I would never do this again and he swore the same thing. This was it. Our last-ditch attempt at having a child rested on that last injection administered at 11pm that night. It was



there that we drew the line in the sand and decided that if our IVF was unsuccessful, then we would continue our adventurous annual holidays and live happily ever after. The bravado behind those words sheltered the emotional and physical pain, which I experienced as all-consuming and just too much to continue to bare. But we did. Somehow. Together. The rest is history.

Having come full circle with our son, born a product of IVF, is an amazing example of purpose. When I look at him sometimes, I find myself thinking "you were the only embryo left and you made it! YOU made it!" This is possibly why I tear up at Mother's Day concerts, moments when he puts his head on my shoulder or when he simply says, "I love you." My daughter, indirectly a product of fertility treatment, was thankfully unshackled from the anxiety that preceded her brother's story, but equally a miracle in her own right. Our story had a silver lining, but as I sit here and reconnect with those memories, the impact has never left me. Part of the impetus of beginning my PhD journey was to attempt to understand more about couples' experiences of fertility treatment. While I still cannot say that I know how most couples who are confronted with infertility experience it, I can say for the couples who participated in this study, their experiences have taught me how, as professionals, we could, at best, better understand fertility treatment experiences and with that, provide support, guidance, education that targets those experiences, and perhaps, a wish from my side, is that it may on some level help soften the journey somewhat for couples going through it.

With my experiences of fertility treatment continuously in the background, a guiding mantra that I found useful and one which informed the way I situated myself and participated in this research, was that "no two experiences are the same". In its simplicity, it informed the way I listened to and interpreted the dynamic and often vibrant exposé of happenings that were significant to the participants' experiences. It directed how I analysed the data and how I chose to report on what I co-interpreted. The quote has implications too for the reader, as the way you encounter the findings may possibly be different from the next person. This idiom speaks for itself as I explore fertility treatment as a great trek within the couple system.

The second findings segment addresses the second master theme identified from the results of this study, namely: "Couples' shared experiences of fertility treatment". This master theme was supported by superordinate themes which convey couples' shared fertility treatment experiences. I use the word "shared" and not "same" experience as these research findings should not be viewed as implying that participants had the exact same experiences as their



partner. I am cognisant that although couples reported pervasive aspects of joint treatment experiences, it may not have been experienced in the same way as their partner. As Logan, in our concluding interview skilfully put it: *"both people are going through exactly the same thing, but you are also not going through exactly the same thing. We are going through this, but we gonna feel different about it."* So how did the couples experience fertility treatment?

Couples in my study portrayed their fertility treatment experiences as permeating beyond intrapersonal psychological experiences into more relational territory. The psychosocial landscape included couples' reflections on their experiences of their partner in treatment, and also extensively recognised their shared partnership experiences of fertility treatment within a larger social context. As such, I understand the findings of this study as portraying fertility treatment experience as a process rather than a single event (or series of events), which necessitates adjustment. The findings of this chapter explored couples' fertility treatment encounters as dynamic embodied psychosocial experiences, recognising the participants' social contexts as important aspects shaping their fertility treatment experiences. Below is a visual representation of how I understood couples' interpretations of their shared fertility treatment experiences:



Figure 9: A representation of the research findings as it relates to a process understanding of coupleship experiences of fertility treatment.

The story begins with couples sharing how they experienced their partner during fertility treatment.



Interpersonal Awareness: Experiencing My Partner During Fertility Treatment

Like most conversations that I have with people, whether it be within, or outside of a therapeutic space, I am mindful of creating opportunities for people to be heard. I try not to say much, listening for their marbles of experiences as they share their experiences with me. There are obvious moments when my input is required or where marbles have been dropped and left to wander off into an untold distance. I noticed this happening during the interviews with the participants of this study. Couples often engaged in a turn-taking exchange, leaving clues as to how they experienced fertility treatment, but not many couples actively engaged in a reflective dialogue with each other about what they were hearing about their partner's experiences or, for that matter, how they were experiencing their partner through their treatment process. This was a curious space for me to wander around in, and instead of leaving those experiences there to fade away into nothingness, I gently asked couples to reflect on their partner's fertility treatment experiences, with the intention of developing an additional image of the coupleship experiences of treatment. Now couples were asked to recognise "you", "me" and "us" in their treatment experiences, which provided thick descriptions not only of their individual experiences, but also required careful consideration of their partner's fertility treatment experiences as they perceived it, as well as eliciting their joint treatment experiences. As this study focuses on the couples' joint fertility treatment experiences, I do not solely attend to the "me" in isolation in this thesis, but rather the "me in relation to us."

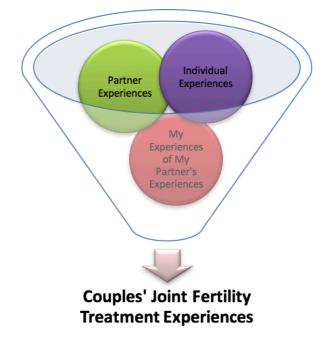


Figure 10: A representation of couples' joint fertility treatment experiences.



Although the figure is limited in representing the dynamic interplay between individual and partner experiences in the joint sharing of fertility treatment experience, it does provide the reader with a visual idea of how I began to understand the unfurling of each couple's joint treatment experiences as the interviews unfolded, and more so, throughout the data analysis.

In an attempt to create insight for participants on their partner's experiences of their fertility treatment process, I asked couples questions that required each partner to reflect on their experiences of their partner in treatment. I feel that my intention to create partner awareness through the process of interviewing was successfully achieved, as Logan, in referring to his partner's responses during the series of interviews, stated that in *"listening to her in the beginning, when we had all the meetings with you, you get a bit of a different side. I never knew that she felt that way about it. The patience...those emotions...the crying..."* How wonderful to hear that couples not only were provided with the opportunity to talk about their personal experiences, but also seized the opportunity to listen to their partner's experiences, and in so doing, witnessing each other grapple with their joint experiences of fertility treatment.

Mirroring the dynamic that unfolded during the interview process, where male and female partners took turns in expressing how they experienced fertility treatment, I too give each a turn to speak individually here in the findings. I attend to male, and then female participants' salient treatment experiences individually, before attending to the couples' joint treatment experiences later.

My choice for beginning with the male voice was motivated solely by the larger number of themes that arose from analysis of the research data. Thereafter, I attend to female participants' experiences of their partner during treatment.

Male Partner Experiences of Their Partner During Fertility Treatment

What I began to notice as I was knee-deep in the data analysis was that participants, in making sense of their joint fertility treatment experiences, reflected on their experiences of their partner during the treatment process. The men in my study had a lot to say about how they experienced their partner during treatment. In particular, men in my study expressed (i) concern for their partner's health during the treatment process, which was accompanied with feelings of helplessness in the face of their partner's emotional and physical pain experiences. In recognising the difficulty their partners were experiencing, some participants expressed



feeling(ii) insecure in the couple relationship as men contemplated the possibility that their partner may consider ending their relationship in the hopes of attaining parenthood more easily with someone else. Although some men in this study expressed concern for their partner's wellbeing, and with that, the wellbeing of their relationship, the process was not absent of elements of (iii) frustration with what seemed like their partner's treatment-related noncompliance.

I begin the discussion by exploring male participants' experiences of concern and helplessness regarding their partner's wellbeing during treatment.

Concern and helplessness. While making sense of their fertility treatment experiences, male participants shared with me their concern for their partner's health during the treatment process. What male participants were primarily concerned about was their partner's general well-being throughout treatment. This concern represented a significant aspect of treatment as they considered their partner's physical and emotional experiences. Ashton vividly illustrated this concern, explaining how he prioritised his wife's health during treatment, explaining that *"as long as she's okay, that's the main thing you know...health-wise, that's the main thing. You can always have a baby, but if it doesn't come and you get sick, you won't get better tomorrow, you know."* Ashton's account aptly illustrates male participants' concern and consideration for the potential consequences of fertility treatment on the overall health of their partner. Their prioritisation of their partner's health in the treatment process was guided by their concern for their partner's wellbeing. Concurrently, male participants expressed feeling a sense of helplessness, as they became increasingly aware and concerned about the physical and emotional toll fertility treatment was having on their partner. In this sense, men experienced their partner as enduring a painful process.

Alongside men's concern for their partner's wellbeing, they expressed experiencing a sense of helplessness as they became increasingly aware of their partner's physical and/or emotional pain experiences. Logan's concern for his partner's physical pain during treatment was accompanied with experiences of helplessness during the treatment process. He shared with me that *"it's bad seeing her like this, I mean in pain, and I can't really do anything."* In acknowledging that there were things that he could do to comfort and support his partner, he conceded *"I can hold her and speak to her and try to get her to stop crying, but I don't want to put her through it again"* and at the same time felt helpless in assisting his partner with her



physical pain experiences. Logan expressed his conflicted feelings around wanting a child while at the same time recognising the possible implications of his partner succumbing to treatmentrelated pain which could potentially result in the suspension of treatment in the future. Logan shared that *"I'll never stop trying, but I'll respect the fact that, if she wants to take a two-year gap, then it's fine. I don't want to do something at the end of the day that's going to break her."* Both Logan and Ashton were concerned about the impact or effects of treatment on their partner. Here, these men's concern lay in how much pain their partner could endure, and with that, how much could they possibly ask their partner to endure before it had potentially devastating effects on their wellbeing? Here, their concern and helplessness were at odds with their personal quest for parenthood.

Men's conflicted experiences during treatment created concern that their partner would choose to end their relationship in an attempt to make their path to parenthood easier, whilst others considered terminating the relationship themselves for that very reason.

Insecurity.Men in this study were concerned that their partner may choose to terminate the couple relationship to seek another partner to make their fertility journey easier. Logan, in sharing his concerns that Mieke may choose to find another partner who may easily fulfil her desire for parenthood, explained against his transgendered background that "for me, for us, it makes things so much more difficult for us having a baby." He shared his insecurity that Mieke "can at any time walk out and say 'You know what? I can't take this anymore, I'm gonna go the natural way, the easier way and get someone that can help me'." Men experienced insecurity as they explored the interplay between treatment and their couple relationship.

Conversely, other male participants considered terminating the relationship themselves to free their partner of their fertility struggle. Bernard, upon reflecting on his partner's treatment experiences, painfully considered ending the relationship with Zethu in the hopes that she can achieve her desired parenthood role. He recognised his partner's treatment experiences as *"very painful" where he explained that "I sometimes think to release her to go get another guy. Then maybe things will be better for her.*" Bernard seemed to worry about his partner's wellbeing and considered ending his relationship in an attempt to make Zethu's quest for parenthood easier.



Although male participants in this study expressed caring and empathising with their partner during their fertility treatment, especially regarding the toll that fertility treatment had on their partner's wellbeing, some male participants expressed that this created concern and insecurity when it came to the longevity of their relationship during such trying circumstances. Whilst men expressed compassion, their experiences of their partner during treatment was not absent of frustration.

Frustration. Whilst men were concerned about their partner during their fertility treatment, and expressed experiencing helplessness and insecurity during the process, their experiences were not without frustration. It seemed that when their partner did not follow their treating doctor's recommendations, men interpreted their partner's behaviour as being uncooperative, which frustrated them. They were also frustrated when their partner ignored their treating doctor's lifestyle directives, which were given in an attempt to secure treatment success. Logan provided an account of his frustration with Mieke following their IUI procedure, after their treating doctor explained "'don't get into hot water'. She takes it boiling hot and that's not good, especially just after IUI." He explained that, "they tell you not to get into hot water, which she did." Logan shared with me how his frustrations lead to conflict saying that, "I mean that's where we were fighting, because I thought that she's not doing her best. She's not giving me her best. "He continued later to illustrate how Mieke had not followed the doctor's recommendations, further illustrating his frustration with what he perceived as a lack of commitment from her side as she was "Lifting heavy stuff and carrying heavy stuff" after their treating doctor explained that "'You must calm down or it's not going to work'."Logan seemed to have observed his partner's behaviour closely during their treatment process, interpreting her unchanged active lifestyle as demonstrating her unwillingness to cooperate with their doctor's recommendations. In this respect, his fertility treatment experiences were shaped by frustration. Men however, were not the only observers during their treatment process, where female participants shared similar experiences as their partner's upon reflecting on their experiences of their partner during fertility treatment.

Female Partner Experiences of Their Partner During Fertility Treatment

Upon reflecting on how they experienced fertility treatment, women shared their experiences of their partner during the treatment process. Women shared that they experienced their partner as (i) both supportive of them during the treatment process, while at the same time recognised that men themselves may be in need of support. Although women expressed feeling



supported by their partner, some women, like men in this study, identified feeling a sense of (ii) insecurity developing within the couple relationship as they explored the possibility that their partner may choose to end their relationship to attain their desired parenthood more easily.

I explore the female voice by first examining their experiences of feeling supported by their partner during their fertility treatment process, before moving on to their interpretations of men requiring support during treatment as well.

Support. Some female participants in this study shared with me that they experienced their partner as supportive during their fertility treatment process. Lesedi shared experiencing Graeme as emotionally supportive during their fertility treatment. In the light of his resistance to show physical support (through avoidance of administering the fertility injections), Lesedi explained that Graeme provided emotional support as *"Graeme was giving me support, even though he didn't want to inject me. I was injecting myself, but he kept giving me hope to relax, you know."* In addition to participants experiencing emotional support from their partner, Mieke expressed experiencing support from Logan through the care, understanding and protectiveness that he demonstrated throughout the duration of their treatment process. She shared that *"he's still caring and understanding and always stood up for me."* Women felt supported when they felt cared for, understood and defended, and in Lesedi's case, where she experienced her partner as motivating her to continue. Whilst women identified and expressed feeling the need for support during fertility treatment, some identified that their partner may require support during their fertility treatment process as well.

Some women recognised and expressed that they experience men as being largely ignored in the fertility treatment process and they too may need support. In sharing a conversation, she had with a friend who was receiving fertility treatment at the same time that she was, Mieke noted that men too may require support and expressed that women could do more to emotionally check in with their partner during the treatment process. Mieke explained that, "*I just asked her 'how is he feeling?' because she's always talking about herself. She never ever talks about him.*" She advised her friend how she would have explored her partner's experiences, sharing that "*I will just ask so that you know how he is doing and she was just like 'ah, you know...'.*" In highlighting the importance of supporting men in the treatment process, Mieke explained that women tend to become focused on themselves, suggesting that the focus should shift from the self, to consideration of the other. Mieke advised that she would "*ask him*



'how are you feeling?' because the woman in the end will say, 'ah, it's just about me, me, me, me, me, me'." Female participants felt that women could do more to ascertain whether their partner was in need of support. What seems important here on experiencing support is that women identify the mutual need for support during fertility treatment. That is, men and women may need to support each other during their treatment process.

Aside from requiring mutual support, female participants, upon considering their partner's fertility treatment experiences, became concerned that their partner would chose to end their relationship as an expedient solution to achieving desired fatherhood.

Insecurity. Parallel to some male participants' experiences in this study, female participants grew concerned that their partner would terminate their relationship in order to pursue an easier fertility journey with someone else. Refilwe elaborated on her all-consuming fear of abandonment as she considered the couple's fertility struggle. She expressed that, "*all the time I was thinking that maybe he's gonna leave me, you know. Thinking it will be next month, next year, next week.*" Fertility treatment experiences for this participant were shaped by feelings of insecurity that her partner would elect to choose an alternative partner to achieve parenthood.

Taken as a whole, it seems that women experienced men as supportive throughout treatment. Women placed importance on acknowledging the role of their partner in the treatment process and advocated that men too require support. Therefore, mutual support during fertility treatment was recognised as an important aspect of fertility treatment. Women also expressed concern, like men, that their partner would terminate their relationship for an easier fertility treatment option. In this sense, it seems that fertility treatment created mutual insecurity for participants in their couple relationship. Insecurity and the need for support seemed to be the common thread as men and women reflected on their interpersonal experience of their partners during fertility treatment. In addition to male and female partners reflecting on their experiences of their partner during treatment, couples also made sense of their fertility treatment as relationship.



Interpersonal Awareness:

Coupleship Experiences of Fertility Treatment

If I was asked how I experienced the concluding parts of the data analysis, and the beginning phases of writing up the research findings, I would describe it akin to the feeling of pins and needles. In a prickly awakening process, as I dealt more and more with the research findings, I became increasingly aware of the requirement to make sense of the pixelated picture that was slowly developing. I experienced this research mandate as one that was loaded with responsibility. The profound, far reaching and abyss-like experiences of fertility treatment were scattered in pockets of the interviews, and I was the person who had the task, privilege and responsibility of making sense of their experiences on the one hand, and authoring their experiences in a manner that retained the integrity of the participants, voices, on the other. A tall order it seemed at the best of times.

When analysing couples' shared experiences of fertility treatment, the undeniable finding of this study was that the process was experienced as tremendously difficult on the couple system. The treatment process infiltrated so many areas of the couples' lives, experiencing fertility treatment as a particularly (i) challenging endeavour, cognitively, emotionally, and financially. Participants shared experiencing their (ii) treated body as a problematic adjunct to their couple relationship throughout treatment. Couples extensively explored their joint experiences of the multiple (iii) systems they chose to engage with, or not to engage with, during their fertility treatment process. I believe these findings are only the tip of their experiential iceberg.

In an attempt to manage the volume of findings, I chose to section the couples' shared experiences into two parts. One part will be discussed here, addressing couples' joint fertility treatment experiences, and the other in the subsequent section of this chapter, which addresses the impact of fertility treatment on the couple system and their mobilisation of coping strategies in the midst of fertility treatment (see pp.206-213), where couples took up an expert role as advisor for others. In this section, I focus on couples' shared emotional experiences, leaving the impact of these experiences on their relationship for later in the chapter. I begin with fertility treatment as a challenging endeavour.



Experiencing Fertility Treatment as a Challenging Endeavour

Couples experienced a number of challenges related to their fertility treatment in the public healthcare context. One of the most obvious challenges identified in my study was the financial expense of treatment and the impact that the cost of treatment had when couples considered different fertility treatment options. I view this as an obvious finding as I have been and still am acutely aware that this study finds itself in a developing country, where each participant in this study highlighted the significant challenge that finances played in their treatment experiences at the REU. More than that though, couples perceived fertility treatment as a challenging undertaking which extended into sometimes less tangible domains. Couples expressed that they experienced fertility treatment as (i) all-consuming, physically, cognitively, and in respect of the time it required to pursue treatment. Other challenging aspects to fertility treatment were the (ii) emotional difficulties couples faced during treatment as well as the (iii) financial implications of treatment and how this shaped their treatment experiences as a challenging endeavour. Fertility treatment was experienced, quite simply, as having taken over their entire lives, making it a challenging experience to manage.

All-consuming intrusive process. From a pragmatic perspective, couples expressed experiencing fertility treatment as an intrusive process, which enveloped their daily routines, their time and their thoughts. This not only placed physical demands on the couple but also time-related challenges, all of which shaped the nature of the couple relationship and with that, introducing a new aspect to the couple's identity.

Invasion of space, time, and thoughts. Mieke explored the couple's all-consuming experiences of fertility treatment as it related to space and time. The invasive treatment experiences were experienced so intensely that Mieke wished for their fertility treatment process to end. She shared that, "I just want this to be over now. It feels like it's invading my space now" adding that "it takes over my whole day" and "I can't think about anything else. I can't do anything else!" Lesedi shared Mieke's experiences of the physical and time-related invasiveness of treatment, explaining how her "tummy was becoming very sore" from the injections and aside from that, the process was difficult because "it's a lot of timing. This one you have to do it at a specific time. The other one you have to do it at a specific time." These participants' accounts emphasise fertility treatment as an all-consuming, intrusive process.



Participants also shared experiencing fertility treatment as becoming a ritualised part of their day. Mieke further shared the intrusiveness of the treatment process as she explained how it became part of the couple's daily routine. The couple described how fertility medication became an ingrained part of their day-to-day living. When medication was no longer indicated during treatment, it impacted their infertile couple identity, leaving them feeling lost, and with a sense that something was missing. Mieke shared that "during the day I'm like 'uh, I must use medication'. It's like there's something missing. You're like 'how late is it now? Yo, I must take it!' and then I'm like 'no you're not on medication anymore'." Logan echoed the enveloping experiences of fertility treatment explaining "Ja, because it was this time, and that time. One o'clock, five o'clock, seven o'clock." Here, experiencing fertility treatment as physically allencompassing meant that couples were required to carefully plan their daily lives around treatment-related activities, such as taking medication. Treatment required that couples carefully negotiated their medication time, portraying the unrelenting aspects of treatment for couples. Logan expressed how medication eventually became part of the couple's daily routine, creating a sense of despondency that this may be the way it will be forever, explaining that "when you open the fridge, it's just medication" elaborating further that "every morning when you open the fridge to have a cup of coffee, that's the first thing that you see, and then it's like 'Do I always have to do this? Is this how my day starts and ends?'" Medication became as routine as drinking coffee in the morning. Participants' resistance to the newly acquired routine of taking and/or administering medication during fertility treatment, at times created an unwelcomed distance in the coupleship.

When it comes to treatment, couples found themselves facing the quintessential paradox: Time is money. One important area that was highlighted by couples was that treatment impacts their presence at work. Couples cannot "afford" to take time off work, yet treatment required that they do, which can potentially threaten their livelihood. The dilemma is such that treatment requires that they pay for services rendered, which requires that at least one partner is earning to fund treatment (unless a third party is footing the bill). The cost of treatment from a time perspective cannot be downplayed, and where possible, requires planning so that the couple feels they can manage both expectations: presence at work and presence in treatment. Another important time challenge was travelling to the REU, where for some couples they lived several hours away from the unit, which now not only cost them travelling time, but also required couples to budget for additional travelling costs. I turn to the first-time challenge,



where couples had to negotiate the time challenges that their treatment presented, which impacted or was impacted by their work.

Couples had two main concerns when it came to their experiences of time challenges. Couples experienced (i) treatment as disrupting work or, (ii) work as interrupting treatment. Couples were faced with ticking both boxes: showing commitment to the treatment process by being physically present, while showing that they are committed to work through their physical presence. Logan, who is responsible for running a division of his father's company, explained how he felt conflicted over wanting to emotionally support his partner on the one hand by being physically present during treatment, but on the other hand, had to tackle work commitments which lead to his absence on treatment day. He shared, "I wasn't here for about two of the times that she's been here because I had to run the business." Fertility treatment was a test of his time management skills with respect to balancing his work-related responsibilities during concurrent fertility treatment. Logan explained that Mieke's work situation is different from his in that she has "a boss that understands. My dad doesn't. I had to run everything here. I can't leave it and just go." In sharing his conflicted feelings, Logan explained that "this is the most important thing in my life, but how am I supposed to go if I don't have a job? "Although Logan felt that the treatment disruptions to his work were different from Mieke's, Mieke explained that as a school teacher, she too was cognisant of the impact that treatment time has had on her work, explaining that "work is gonna start complaining. I'm taking off too much. I've got this vibe at school." The time challenges that fertility treatment places on couples, required couples to manage their work-related responsibilities, as well as the treatment related expectations. Not an easy task for couples. On the flip side, work in some instances, interrupted treatment goals.

Depending on the couples' occupation, work interrupted their fertility treatment aspirations. Lebogang explained how the couple's work obligations interfered with continuing their fertility treatment plans, explaining that "we saw a doctor a few times who told us the problem. Then after that we went to deployment and that's when everything stopped. We both went to Lesotho, so this year we started again with this procedure again." Couples not only had to negotiate time away from work to be physically present for treatment, but for some, were confronted with negotiating the challenge of travelling time.



Treatment also presented couples with time challenges when it came to other facets of treatment. A moment that stood out for me was when I was talking to Lebogang and Sipho prior to beginning our interview. In the initial meet and greet phase, prior to beginning the recording of their interview, they shared that they lived four hours away from the REU. This meant that an entire working day was spent all-round when it came to their fertility treatment experience, as travelling did not only mean there was a financial cost incurred in getting to the REU, but it required the better part of their day to be set aside for a single consultation or procedure. This, coupled with time spent at the hospital, consultation time, follow-ups, and time dedicated to administering medication, meant that treatment cost this couple a large proportion of time.

Couples expanded on their experiences of fertility treatment as an intrusive, allconsuming process highlighting its permeation of their thoughts as well. In sharing their experiences with me, couples identified experiencing repetitive thoughts, which repeatedly drew back to their fertility treatment. Keketso shared how all-consuming the process became for the couple, especially as he attempted to gain perspective on infertility as a temporary issue requiring the couple to make informed decisions. It seems from how he gave his account, that he experienced infertility as a cognitive process that replayed over and over again, in an attempt to come to a well-thought-out solution for the couple's fertility difficulty. Keketso shared that "it will run and ring in your mind. Every time in your mind, in your mind, and in your mind." Explaining how he attempted to gain perspective in the midst of these repetitive thoughts he shared that "at the same time it's ringing in your mind again that you love this person, and we can cope, and we can move forward. This is only a challenge. Let me not take permanent decisions for a temporary situation." Although participants may have attempted to find and maintain perspective, it was not always easy as treatment-related thoughts replayed continuously. Logan expressed experiencing intrusive treatment-related thoughts, sharing that "my mind was running around and racing with everything." The couple also became aware of their own negative thoughts surrounding their treatment process, sharing that "sometimes it feels like, you know what? Why? Why are you trying? You start to think about all the negative things." The negative thoughts stemmed from uncertainty regarding the success of treatment. Logan shared the conflicted, excited, and doubtful feelings that he experienced, explaining that "I'm enjoying it, but it's that, you know, that little bit at the back of your mind telling you, just don't get too excited. Don't!" As it relates to couples' thoughts, it seems that fertility treatment became an intrusive process, impacting how fertility treatment was both perceived and later dealt with as a couple.



Other than experiencing fertility treatment as physically and cognitively demanding, couples also expressed requiring much needed time to dedicate to their fertility treatment, which was not always easy to manage. Additional challenges highlighted by the participants were the financial and emotional aspects of their treatment experiences, which created difficulty and required adjustment. I view the section on the emotional experiences of fertility treatment (see section on emotionally challenging process, pp.200-205), as contextualising the concluding section of this chapter dedicated to couples' coping strategies during fertility treatment. I now turn to participants' experiences of fertility treatment as a financially challenging process before exploring the emotional challenges couples endured during treatment.

Financially challenging process. A startling finding was that four out of the eight couples in my study had no choice but to discontinue treatment due to their inability to financially sustain it. While there were other reasons for the other three couples discontinuing their treatment at varying points of their treatment processes (such as conception and a need for emotional and physical distance from the process), this financially based finding is a bleak one indeed. Whilst this does not necessarily portray, nor imply that it reflects the current South African statistical image of the treatment fallout rate due to lack of funds, it was a pronounced finding of this study nevertheless. Half of the participants in this study, at various stages of treatment, had no choice but to discontinue due to a lack of available funds. I have contemplated the injustice of this time and time again and as I make sense of participants' financially challenging experiences of fertility treatment, I have wondered where this has left these and other couples who have had no other choice but to park, or at its worst, surrender their dream of being a parent because of the lack of affordability.

In sharing their experiences with me, couples helped me to better understand how they weighed up their limited personal finances in respect of treatment costs against their desire for parenthood. In making sense of their fertility treatment experiences, there was no escaping the financial costs and with that, the financial challenges inherent in accessing and/or continuing fertility treatment. Couples were required to (i) plan their finances accordingly, which meant for some couples they were faced with (ii) postponing personal short-term goals, or were prepared to (iii) face financial ruin in the quest to have a child. Despite couples' limited financial capacity to fund their fertility treatment, each demonstrated a resolve to continue with treatment against financial odds until they either conceived successfully or discontinued treatment as they simply could no longer sustain it financially. Logan, in sharing the couple's



determination, said that "I won't give up. I know that it's expensive, it's money, I mean we've taken out so much already." Wanting a child and engaging in fertility treatment to attempt to have one, meant that couples had to plan their finances.

Although treatment in the public health sector is cheaper than privately offered treatment, couples who were undergoing public-based treatment were faced with wanting a child at a cost, which for most, was not easily negotiated and required that they plan their finances. Since finances could be viewed as a cause of stress in the treatment process, it was important for couples to have a clear idea of the cost implications going in. Where costs were unclear, this seemed to introduce an additional element of uncertainty to the treatment process. Logan, in demonstrating his experience of financial uncertainty shared that "*I'm not certain, and I don't know if it's gonna go on our account, I don't know if I have to pay, I don't even know when it's going to start.*" Clarification of costs enabled couples to plan for the financial implications of treatment. Logan explains "when I got the paperwork, I just had to sign it, and then we had to speak finances which, thank God, my father helped with." The clarification of treatment costs enabled couples to plan their finances accordingly.

The treatment protocol also impacted planning since the type of fertility treatment prescribed had varying financial implications for couples. For example, IUI was experienced as a more affordable treatment option in comparison to IVF. Lesedi explained how the cost implications informed their decision to try IUI as an initial treatment option. Lesedi shared that their treating doctor "explained to us the cost, saying artificial insemination costs so much, the IFV is more expensive, but obviously not as expensive as your private institution." and "financially, it's straining as well because if your eggs grow faster you don't have to buy more medication but if it grows slower, it means you have to go back and that is more money. "Mieke, in describing the expense of IVF treatment, illustrated how the high treatment costs placed additional pressure for the treatment to be successful, as it became their last hope at achieving a successful pregnancy. Mieke, in illustrating the enormity of the financial investment IVF treatment required, made reference to numerical values in narrating the couple's experience. Although the finances that she quotes do not necessarily represent an accurate indication of how much IVF costs per se at the REU, what it does do though is successfully illustrate the financial challenge this type of treatment posed for the couple: "Wow, this is the big one you know. The money obviously, I mean it's not costing R10. You always think 'okay this has to work. We don't have R25 000 again', seriously." In the end, couples were required to pay for



treatment. Most couples in this study did not have readily available funds to afford this type of treatment, so were faced with postponing short-term goals, facing putting themselves in debt or discontinuing treatment.

The financial implications of treatment meant that for some couples they would need to consider postponing personal short-term goals in order to cover the costs of treatment. Logan and Mieke decided to postpone their wedding goals in favour of pursuing IVF treatment, which also required the couple to enlist the financial assistance of family. This finding indicates that fertility treatment costs are still significant for patients undergoing treatment in public healthcare. Logan shared that "my father's got money for when we wanna get married. He's got money for my brother and me for that day." In explaining the importance of treatment to them, Logan explains that he is going to "once again ask him if we can take that money for this. So, we are postponing the wedding." This couple evaluated their concurrent plans of having children against those of getting married. Here, they found themselves prioritising their goals in order to plan their finances accordingly and for this couple in particular, it meant postponing the possibility of financial ruin.

Couples elaborated on the financial strain that treatment placed on them. The paradox between wanting a child on the one hand, and not being in a financial position to afford treatment at the time, on the other, amplified the experience of difficulty for couples. Keketso explains that it is "a very difficult journey, I can tell you that, very difficult...it is extremely damaging because when we started the whole process, I wasn't financially stable, she was not working, she was still going to school." Here, Keketso highlights the financial position of the couple at the time of engaging in treatment. However, Keketso, like Logan, was determined to endure the financial challenges of treatment. In sharing the couple's financially challenging experiences, Keketso expressed the financial strain the treatment process placed on the couple, which ushered them in to critical financial trouble. Keketso shared that "I've learnt to survive, even in the most difficult situations, I have learnt to survive. I can tell you that I will survive financial crises." Despite being faced with the paradoxical situation of wanting a child and not being able to financially afford fertility treatment costs, this couple in particular demonstrated that they would financially overextend themselves to engage in treatment. This injects an additional financial challenge as couples now have the stress of fertility treatment and the costs of everyday living to deal with. For Keketso and Refliwe, Zethu and Bernard, George and



Mapuleng, and Rozalia and Bongani, this meant the suspension and/or termination of treatment due to the financial challenges presented by accessing treatment.

The research findings communicate that couples' fertility treatment experiences can be understood as an all-consuming process, intruding on couples' experiences of their daily life. Enveloping couples' routines, thoughts, time and money, couples experienced fertility treatment as a challenging process all-around. Another challenging aspect of couples' fertility treatment experiences were their experiences of the treated body as a problematic adjunct to the couple relationship.

Challenges of the treated body. Like a Polaroid picture slowly developing before my eyes, so too did the emergence of the treated body as a significantly challenging aspect of couples' treatment experiences. Like a new person thrust into the lives of couples, so too was the challenging development of the treated body as a problematic addition to their partnership. Participants expressed that they experienced the treated body as presenting a (i) reproductive hurdle, where, in its treatment, obtained a (ii) problematic illness identity, both within and outside the context of the couple relationship. In an attempt to garner control in the treatment process, the (iii) administration of medication served an important function, albeit that medication held a precarious position in the treatment process. In relation to the treated body, men in this study reported feeling like a (iv) bystander which was not only perpetuated by the medical attention given to the treated body, but also through communication practices during consultations. The discussion begins with an exploration of participants' experiences of the treated body as a reproductive hurdle.

Experiencing a reproductive hurdle. Couples who participated in this study shared experiencing the treated body as a problematic adjunct to the couple relationship during their fertility treatment. In making sense of their joint experiences of the treated body during treatment, couples highlighted their experience of the treated body as an obstacle to conception. Logan, in sharing the couple's treatment experiences with me, described how his body represented a reproductive hurdle to their parenthood aspirations. Only this couple, and a select few knew about the couple's reproductive difficulties. The privacy the couple maintained around their reproductively-challenged bodies, made it a perplexing situation for others to understand and with that, limited the couple's experiences of feeling fully understood. Logan disclosed that *"it's not like that little egg's is gonna come running to Mieke and then it just*



happens. I mean, we have to be here. That's what people don't understand" although, I understand that they don't know my background, so they think everything is normal." He described how the couple maintained his treated body's privacy by "leaving it." But when it came to talking about it with their friends that knew, he expressed his frustration with their lack of understanding, asking their friends, "is the baby gonna come crawl up her leg? You can't just leave it to happen naturally and they said, 'oh, sorry, we forgot about you'" Logan understands where their friends' forgetfulness comes from "because it's normal for them to think I'm a biological male, so sometimes they say 'sorry, we forgot about it'" which "makes it worse to remember. I was not in a good place and I thought maybe I should just leave her and then be alone by myself" this would give her the opportunity to meet a biological male" then "she doesn't have to go through all of this. If she wants to be pregnant then, boom, and then she's pregnant. But I won't be able to do that. I'll do it, but I won't survive." As Logan contemplated the reproductive obstacle his body placed, he considered how their friends do not always remember or fully understand that their reproductive journey will always be associated with physical challenges. The enormity of this challenge he considered against the simplicity of ending his relationship with Mieke, and the emotional pain that too would bring. This speaks to the difficulty of the process and a desire for this participant to employ distance, albeit not a solution either wanted to entertain in the face of an "illness identity" that unfurled.

Acquiring an unwanted illness identity. Participants shared how an inadvertent illness identity developed throughout their fertility treatment process, which informed people's interactions with the participants. In this way, the invasiveness of fertility treatment permeated interpersonal interactions, impacting perceptions in those interactions. Mieke described her interpersonal experiences during fertility treatment as particularly frustrating because "everyone treats me like I'm sick. I'm not sick! Even at work 'are you feeling okay today?' 'Ah! Don't look at me, I'm fine, I'm not sick' You see, I think that's what irritates me." This participant interpreted people's concern for her health as an overt assignment of an illness identity, which she found increasingly frustrating.

The function of medication in the treatment process informed, in part, the development of an imposed illness identity in the couple relationship. This seemed to be a sensible assumption to me, given that medication is generally understood to be indicated for sick people. Logan was extremely mindful of the importance of medication as he assumed the role of promptly administrating medication to Mieke. The ritualised rigour of administering



medication further entrenched the illness identity that Mieke vehemently refuted. Logan explained that "when it comes to the time of the medication, it's like a clock or an alarm going off inside of me. I realise, wait a minute!" Logan's punctual medication reminders were met against Mieke's resistance to an illness identity, which showed up in her procrastination when it came to taking medication. She explained that, "I don't want it to be a sickness." Mieke's resistance to medication placed strain on the couple relationship throughout their treatment. In an attempt to address Mieke's resistance to medication, Logan shared that "when we started talking about it "he realised that was "her way of dealing with everything that's been going on inside of her. "Logan explained Mieke's resistance to medication as her wanting "to try and get out of the fact that it's painful, she's been trying to push the time up so that she can think about how she can get over this pain when I inject her." Logan seemed to understand part of Mieke's resistance as a function of the physical pain that Mieke experienced in the administration of the injections. However, it was also coupled with her active resistance against an unwelcomed illness identity. Although this couple experienced medication as further validating an illness identity during treatment, it was also recognised as fulfilling some sort of control function in the treatment process.

As the couple made sense of the difficulty that medication introduced in to their relationship, Logan clarified the personal importance that monitoring the administration of medication had for him. Coupled with his continuous commitment to fertility treatment-related research, which informed the instructions he gave his partner, he explained how the continuous monitoring of medication gave him a sense of control over at least one element of the treatment process. He explained this in contrast to the lack of control he felt when Mieke was undergoing a treatment procedure, and his experiences of frustration and helplessness, where "*up until now I had some sort of control with the medication, the research and telling her what to do and at what times*" but when "*she goes into that room, it's out of my hands and I can't do anything and that's what's frustrating me.*" This couple shared experiencing the medication as informing an illness identity and on the other hand, exercising control over an element of treatment in the instances where their body is not in treatment per se. This was a finding of this research project.

Bystander. Couples experienced the treated body in a number of ways, one of which was underpinned by distance. Couples expressed how the feeling of distance was not always



understood by their partner. Lesedi, in sharing her experiences of her husband as a bystander to her treated body, explained how her husband was unable to fully understand her treated body experiences as he was not on the physical end of the treatment. Lesedi explained that, "the thing is for my husband, he can only be there, but he wouldn't experience it because it's happening on my body, you know." This experience of distance can be further detangled. The evolution of distance in the treatment process can be unintentionally created from the very beginning of the formal investigations. As the identified patient is often the female partner, it can leave the male partner as a bystander to the treated body. In exploring Lesedi's account again, it seems that she feels that Graeme does not experience treatment fully, as his body is not involved in the process. Logan too explored feeling like a bystander as he explained that "I think the fact is that no-one really understands what she's going through" because "I don't need to inject, I don't have hormones running sky high. She's the only one, and I'm trying to understand, but I mean, I'm not the one sitting with all these marks "and "at the end of the day, I mean, to me it's emotional, but it's not that bad because, I mean, my hormones are alright." Here, Logan's bystander experiences are understood against the difficult physical processes the treated body endures as a result of fertility treatment. Whilst he can empathise, he concedes that he cannot fully understand the experiences of the physically treated body. In these instances, he feels a sense of distance in the fertility treatment process.

Mieke, in sharing an experience of a friend who was receiving fertility treatment at the same time as her and Logan, recognised and echoed the importance of acknowledging and including the male partner in the treatment process, sharing *that "women push them away. Like* 'ag, you know what, I'm the only one going through this'" and explains that with her friend that "I just ask her 'how's he feeling?' because she's always talking about herself, she never ever talks about him, so I will just ask so that you know 'how's he doing?', and she's just like 'ah, you know.'" Elaborating further on the experiences of the male as a bystander during fertility treatment, Mieke shared that "it's wrong because she must also involve him! Get what I'm saying? Like ask him 'how are you feeling?' because the woman at the end will say 'ag, it's just about me, me, me, me, me'." Logan identified and explored the incongruence of only recognising the treated body as an overarching facet of treatment and in so doing, creating a bystander role for the partner during the treatment process.

Logan explored his bystander experiences during treatment through exploring the treating doctor's role in creating distance during consultations. Explaining the importance of



the male partner in the treatment process, he commented that "obviously, you need the sperm from your husband, so come on, he's got 50% in it. He's just as important as you are in this thing. If you are not there, what you gonna do?" Logan shared how treating doctors "also tend to concentrate on the ladies. Maybe men are seen when they talk to them" explaining further that men "will just sit there or be on their phone because guys don't always ask questions." It seemed that Logan felt that doctors may perceive men as passive participants, who seem distracted by technology, and present as generally disinterested as they do not ask questions. He experienced the treating doctor as misinterpreting the female partner's questions for a more active role in the treatment process, and therefore, demonstrating more interest. He shared that "they think 'well now, she's the lady whose asking me all the questions, so she must be worried" and "the guys just sit there, but it's not like men don't wanna ask, they just don't know what to ask" and "that's the problem, they don't know what to ask. They try to get the information from you as a doctor." Logan explained that this dynamic could change "if they had more information, they could say 'oh, we can ask this, or this,' but they don't know what to ask. So, it's lack of knowledge and I think also lack of support." He understood how this disinterested perception could be shaped by men's limited input during consultations. The lack of input during consultations could at times be better understood as reflecting a possible gap in knowledge, which is subtly created by their exclusion in the treatment process. He identified communication as a two-way process, where if doctors provided more information to the partner not receiving physical treatment, it could possibly create opportunities for stimulating more questions.

It seemed that participants experienced an unexpected addition to their couple relationship when undergoing fertility treatment, where the identity of this addition was experienced as a problematic one, requiring both understanding, treatment, and the inclusion of the non-physically treated partner in the process. I explore recommendations as it relates to this aspect of these findings in the Discussion Chapter, as I believe the couple requires a cohesive and supportive treatment approach in this regard. Now though, I conclude the discussion of the aspect of the findings that explores fertility treatment as a challenging endeavour, by exploring couples' experiences of fertility treatment as an emotionally challenging process.

Emotionally challenging process. Forming a qualitative psychological study, it is no surprise that the couples' accounts of experience in this study would be stippled with emotion. Although at first, what seemed like widespread emotional experiences soon began to form a



picture portraying couples' experiences of the dynamic interplay between emotional lows and highs of treatment. Although I attend to the (i) lows and then the (ii) high experiences separately, participants' experiences can be viewed as representing a process, where for example participants may have swung between feeling hopeful one day, to hopelessness and disappointed the next, depending where they were in their treatment process, what the outcomes of that particular treatment were and what the process was doing to them.

I explore couples' experiences of the emotional lows of treatment prior to moving on to their experiences of the highs. This decision was firstly guided by the sheer volume of data derived on their treatment-related lows and secondly, the discussion seemed to flow into a more fluid exposé of their treatment-related highs and coping. The dichotomy between stress and coping became clearer as I worked closely with the data.

Experiencing emotional lows. Couples' narratives were dominated by their experiences of treatment-related lows, which were shaped by (i) pain and difficulty, (ii) anxiety and stress, as well as (iii) sorrow and disappointment. These emotional lows underscored the emotionally challenging fertility treatment experiences of these participants. I explore the participants' experiences of treatment-related lows by first exploring the pain and difficulty they endured during their treatment process.

Pain and difficulty. To say that couples experienced fertility treatment as an emotionally difficult process would be a deficient account of their experiences. Perhaps Keketso's words emphasise this point: *"it was not an easy journey. It was not an easy one, and I didn't take it to be, because you are dealing with the unknowns and it's hard to deal with the unknown. It's hard."* As I reflect on the emotional experiences expressed by the couples in this study, each participant reported experiencing treatment as an incredibly difficult and painful journey. Although only a select few of the participants' experiences were noted here, as they seem to best capture this aspect of treatment experience, it is by no means discounting that participants' experiences of fertility treatment were shaped by an emotionally painful and difficult journey. Refilwe shared that *"sometimes it's hard just thinking of 'oh no, I'm not gonna fall pregnant now!'"* describing their fertility treatment journey as a *"long road. It's painful. Sometimes I took all my anger out on him. Sometimes I cry and sometimes he doesn't understand how I feel. It's painful."* Refilwe's account tells a story of a long and painful fertility process which elicited a number of mixed emotions for her. Bongani highlighted the pain that he and his wife



experienced in their struggle to conceive as he shared that "it's painful not to have a baby, you know. It's not an easy thing because I think my wife is going through a hard time." In explaining the importance of the fertility treatment and the hope that their treatment process would bring an end to their anguish, he said, "I think this is the last hope we have. We hope and believe that all the processes that we are going through now will help us." Bongani shared that it can be difficult to remain hopeful because "if you are deeply involved in a thing like this one, it's a very heavy task to be going through." Mieke referred to their joint experience of the treatment process as a "schlep", a Yiddish word referring to the difficulty of the process. She explained that, "the thing is, it was such a schlep. It was long, I was like up, down, going again and again." Elaborating in a later interview that the difficulty that underlined the process continued to be one that required endurance, where "for me it's just ... Yoh, it's a schlep!" Rozalia highlights further the effort that is required in the midst of a difficult treatment process in saying that, "it's not an easy task to do, it's a task that someone needs to put their effort behind" where "if you put a shoulder behind the wheel, you are pushing it forward, together. You always manage to push it forward the direction that you want to." Here the participants' experiences of treatment were shaped by the difficulty of the process which required physical and emotional endurance to continue and the commitment of time to engage in treatment.

Couples' experiences of treatment-related lows were not only shaped by their experiences of pain and difficulty, but were also stippled with anxiety and stress for some participants in this study.

Anxiety and stress. Participants' experiences of treatment-related lows were also shaped by their experiences of the anxiety and stress related to differing elements of their treatment process, such as lifestyle recommendations, the type of treatment and the treatment outcomes. Initial fertility treatment experiences and subsequent consultations thereafter were experienced as a stressful source of their treatment-related lows. In some instances, lifestyle guidance was experienced as stressful as it set treatment-related expectations which needed to be met. Rozalia, described how lifestyle guidance given by her treating doctor to lose twenty kilograms in weight, elicited anxiety and frustration. She explained that "Yoh, it was tough!" when they initiated treatment and now "I was frustrated! In fact, every time when I come here, it's like I'm nervous or something." Expanding on their initial stressful consultation experiences further, Rozalia explained how their treating doctor "took me to the scale" and said that "before we can start the process I must lose twenty kilograms, because I was weighing 107kgs" at the time.



Alongside experiencing initial consultations and lifestyle advice as stressful, participants shared that their stressful treatment experiences were shaped by the type of fertility treatment prescribed, and in particular, IVF treatment.

Stressful fertility treatment experiences were also shaped by the type of fertility treatment indicated and the treatment outcomes. Couples' undergoing IVF treatment expressed that it was a particularly stressful experience as it was a physically painful process that made participants question their resilience to endure the process. Mieke explored the stress she experienced against the backdrop of her "strong" resilient identity and how the process conflicted with this identity: "I don't like crying, I just wanna be strong all the time, but ja, it's still stressful." Explaining that, "I just worry about the pain" of IVF treatment. Logan agreed that, "it's still stressful, a lot!" as he contemplated the procedural aspects of treatment. His anxiety centred on the accuracy and success of treatment procedures, especially as it related to their embryo. He worried that the embryo would remain in the catheter following the embryo transfer procedure, sharing that, "I had a dream a week ago" that their treating doctor would "make a mess-up when they put the eggs back because I keep thinking of that little straw, 'what if they inject and they think it's in, but it's still in that straw?"Logan placed immense importance on their embryo, and shared the anxiety that he experienced as he considered the possibilities of the accuracy of the procedure. Participants' anxious fertility treatment experiences were shaped by their concerns regarding the accuracy and success of their fertility treatment procedures, as well as the success of their treatment. As I understand it, couples' stressful fertility treatment experiences were related to differing elements of the treatment Participants shared experiencing anxiety as they anticipated their approaching process. consultations with their treating doctor. Participants shared experiencing IVF treatment as a physically stressful process which tested their resilience to withstand and continue treatment. Participants' stressful treatment experiences also related to their concern about the accuracy and outcomes of treatment.

Another facet which shaped couples' fertility treatment experiences as an emotionally challenging endeavour, were their experiences of sorrow and disappointment.

Sorrow and disappointment. Participants' treatment-related lows were shaped by moments of profound sorrow, disappointment and hopelessness, especially when treatment had been unsuccessful. Lesedi described experiencing immobilising sorrow when her menstruation



signalled that their treatment was unsuccessful, sharing that, "every time I got my periods I cried. I don't wanna lie, I cry. I just don't do anything, you know. So, it's a very sad process to go through." Elaborating further on the impact of her sorrow, Lesedi explained that, "for me, it has not been very easy, you know, when I get my periods. I go from a hundred smiles to zero smiles." When asked how she could put this experience into one word, she whispered, "devastating." For Mieke, her sorrow went hand-in-hand with irritability, as she experienced what felt like emotional weakness or an inability to cope. She explained how her experiences of sorrow lead to the development of regressive, self-soothing behaviours as a way to manage her feelings, sharing that she said to herself, "Oh, stop crying Mieke! Really, just stop crying!' I actually started to sing to myself and then I just feel like, really, you're not a baby, just go on, it's not the end of the world." Sorrow and disappointment seemed closely connected when exploring the emotional experiences of fertility treatment.

As couples explored the emotional challenges related to their fertility treatment experiences, it became increasingly clearer that couples experienced different emotional reactions to different treatments. Mieke, in expressing the emotional impact of IVF, painfully describes, "I was crying my heart out...I thought I'm just gonna tell these people my grandma died." Comparing an IVF experience to grieving a deceased relative is a profound expression of the emotional impact of treatment. Here, Mieke was discussing her experience of IVF treatment upon returning to work directly after treatment. Her experience was not related to treatment outcomes, but only on the experience of being treated. It provides insight into the emotional toll fertility treatment can have on couples. In this vein, Logan shared the emotional challenges, and with that, the lows that the couple experienced during their IVF treatment. He shared with me how their treatment prevented the couple from experiencing positive emotions during the treatment process, explaining that, "we haven't really been super excited about anything lately. Nothing really gets us excited." Mieke explains that, "at the back of your mind you know you can't get really excited because you got this thing that's hanging in the air". Here Mieke and Logan identify that one of the challenges of treatment is the difficulty in accessing or experiencing positive emotions. All too often, with sorrow came disappointment.

Disappointment seemed to have become a likely component of treatment, with couples confronting disappointment all too often in their treatment process. Bongani explained how the couple viewed their disappointment as a challenging endeavour, and how they chose to manage it as such. Bongani shared that it is *"one of the challenges that we are facing in life, you know,*



there's a lot of things in life that can make a person to be more hurt, you know." He explained further that treatment reminded the couple "to always make room for disappointment in your life. If you don't do that, you are going to have problems." He explains that treatment required perspective where "you shift some things away from your life. You just move it away from you to be able to concentrate. If you keep all that you are coming across, then you will have a miserable life, "so, they keep "focused on the journey that we are taking and that's it." Here Bongani conceptualises fertility treatment as a challenge to be overcome, which helped him to remain focused and to maintain perspective on the bigger picture, albeit that he experienced disappointment.

Although couples expressed experiencing fertility treatment as an emotionally challenging endeavour, as underpinned by pain and difficulty, anxiety and stress, as well as sorrow and disappointment, couples too identified treatment-related highs albeit in the midst of an emotionally challenging process.

Experiencing emotional highs. As I considered the emotional "lows" of couples' fertility treatment experiences, and what this meant for these participants as they encountered their fertility treatment process, I wondered whether, in part, these emotionally challenging experiences could be attributed to, or set against the backdrop of their hopeful experiences.

Hope. There were a number of factors that created hope in the treatment process, one of which was how the body was responding to treatment, signalling that success could be achieved. Kerry-Lee eloquently shared how "the other day" their treating doctor "found a big follicle" and she said, "I could expect twins so, I was very excited, and from then on my hopes are high." Rozalia, in sharing her hope as a result of their treating doctor's reassurance that there were no obvious fertility issues that she could pick up, illustrated the intensity of her hopeful experiences as she clung desperately onto the doctor's words. She shared that their treating doctor "said to me 'No, no. You will get pregnant. I don't see anything wrong'. It was like having that hope, having that hope, having that hope." Although Bongani too shared experiencing hope, it was coupled with pain during the treatment process, where "it's pain and hope as well because what if we manage to overcome the problem?" Bongani elaborates on the conflicting feelings, explaining that "it's pain and hope you know, because this is the hope that we got and I think it's the last hope. We really think this will help the situation. If after going through this, and this one fails, eish!" Contemplating both the hope of conceiving a child as a



result of enduring treatment, against the possibility that the treatment may be unsuccessful, was a painful emotional experience for participants. As a way to manage their conflicting feelings and to safeguard themselves from experiencing disappointment and pain, some couples exercised caution when it came to embracing hopeful treatment experiences.

Some participants took a middle-road approach, attempting to be cautiously optimistic during treatment, possibly as a means to buffer potential disappointment and preserve hope. Ashton described being cautiously optimistic through attempting to maintain a clear perspective on the process. He shared that, "*if it doesn't go well, there will be a next time. Hopefully it does work but as long as she's okay and everything, that's the main thing, you know.*" Logan highlighted how statistical success rates elevated their hope for possible positive treatment outcomes, and how they attempted to reign their hope in by "*reading a lot and just from listening to other people that have done IVF instead of IUI. The success rate is better, so it's giving us hope, but still, we don't want to get too excited.*" Although participants attempted to exercise caution in their treatment-related hopefulness, it seems that participants were mindful of the possibility of disappointment in the process.

I have chosen to attend to couples' experiences of coping with fertility treatment prior to moving on to a discussion on participants' joint experiences of the social contexts that shaped their fertility treatment experiences. There, I explore the multiple social contexts that were identified and the role these systems played in facilitating or conversely, not facilitating coping with fertility treatment.

Experiencing Fertility Treatment as a Coping Opportunity

I view this section of the findings as a victorious one. Coping during the most trying of circumstances and taking with them the lessons that their treatment process had taught them, were triumphant aspects to participants' treatment stories. Was the journey without struggle? No, and I do not think the findings leave that impression either. But the resilience of the human beings is demonstrated beautifully by the participants of this study who attempted to capture the silver lining that was often so very difficult to see in the midst of their darkness.

Up until this point, the findings presented in this chapter talk about how couples make sense of their joint fertility treatment experiences. The story of couple survival, shaped by their resourcefulness, is what I attend to next. Couples, in sharing their experiences with me, shared



what helped them get through trying times during their treatment process. Couples attended to the role of (i) communication in helping them cope, where for some, openly communicating their experiences helped them cope, while for others avoidance of communication was more useful. Their focus on (ii) conflict resolution became a coping tool for some couples, where they learnt the value in resolving conflict differently. Participants highlighted (iii) stress management strategies that they developed to neutralise treatment related tension and others referred to an awareness of their (iv) treatment outlook, where they made a conscious effort to remain positive, embrace acceptance of the outcomes and possible disappointment that may be an inevitable part of treatment. I explore communication first before moving on to a discussion of conflict management strategies employed by the participants of this study.

Communication as a coping strategy. Participant experiences as they related to the role and function of communication in helping them to cope with fertility treatment, was a conflicted one. Some participants engaged openly about their treatment experiences with each other, while others avoided communicating about it. Rozalia explained that their avoidance to communicate about their treatment process as a couple, was motivated by her attempts at managing her treatment-related pain. She shared that, "we normally don't talk too much about this. He's seen that when I talk about it, I'm hurting." Here, Rozalia expressed that their preference to not communicate about their treatment process was a way for her to manage her own feelings and a way to shield her partner from her pain. Logan too expressed that noncommunication was a way for the couple to manage the all-consuming nature of their fertility treatment, explaining that, "every day, the medication is there, on time" by trying to create unaffected spaces in order to cope: "I don't want to speak about it too much and to make her think that her whole life is just about IVF. So, we don't speak about it at home." While it may seem that couples may have preferred to either avoid or engage in communication, this is not a hard-and-fast style. This was especially noted with Mieke and Logan, who went through moments in treatment where they did not want to focus their communication on treatment, while at other times they valued the role of open communication as a way of coping. Mieke shared how communication can be a supportive element in the treatment process, recommending that couples should be "talking about it, you know. Just start to talk about it, and say all the good things" and "just tell each other, 'ag, you know what, it's gonna be fine."" Communicating was perceived as supportive and in this instance, had the potential to aid the couple in coping with the demands of fertility treatment. When I asked Mieke what partners could do differently, she put it quite simply: "Just talk to her. She needs someone." While there are coping benefits



to minimising fertility-dominated conversations, there are also benefits to talking about it. What seems beneficial in the fertility-dominated talk, is reframing the conversations into more supportive-, than problem-dominated conversations, thus minimising conflict.

Conflict resolution as a coping strategy. A natural continuation of the aforementioned discussion on communication (or avoidance of communication) as a coping skill, was learning to effectively resolve conflict during the treatment process. Couples who were trekking through an arduous treatment process experienced a number of emotions (as addressed earlier in this chapter, creating the possibility that conflict could arise. Some participants identified that (i) calm expression of emotion, and (ii) supporting one another were useful aspects to resolving and/or managing conflict during treatment.

Logan, in sharing their experiences on learning conflict resolution, gave an account of their journey by explaining what the couple found helpful. He explained that in resolving conflict with his partner that he said, "'listen, if it gets to you and if you are gonna get irritated, talk to me, don't fight with me" or just "ask me, because I can't do anything about it. I can't stop the irritation because of the medication, so it's gonna be there, but just speak to me nicely". Here, Logan explains how he guided his partner in managing and expressing her irritability in a manner that was less conflictual. Logan understood her treatment-related irritability as being related to the medication she was receiving during treatments, and although he expresses feeling helpless in this regard, her calm acknowledgement of her irritability would result in calm management. Logan expressed that if Mieke could manage to calmly talk about her irritability, then, "I'll try see what I can do. Maybe if you need me to do something or you need me to take something out your way" explaining that if "you just need me to just leave you alone, I'll do it but not to fight about it, orstart shouting". Logan explains that his preference for calm discussion is because "at the end of the day people get, especially from the guy's side, you are keeping so much emotion inside of you because you don't want to show it "explaining that, "if you fight, then there's, I think, the aggressiveness in the guy, it gets to the point where you will break someone's neck just to get rid of all those feelings." Logan's wish to avoid conflict seemed to stem from his concern about his own internalised emotions, which he feared would result in an aggressive outburst if not handled calmly. Logan goes on to share the precarious balance he experiences between leaving his partner alone to deal with her emotions, and at the same time, attempting to avoid his partner feeling unsupported. Logan shared, "with us it was just asking questions. If something, well I could see it just now, it gets irritating, 'just back off! Just leave



her" but felt conflicted in his approach where he expressed caution, "don't leave her alone for too long because she's going to think I'm not supporting her"so "it's just to give her space for a minute to calm down"andthento "ask her 'what is wrong? Why do you feel like that?' I mean 'what can I do to make it better for you?' and ja, that's what helped us." Logan explored the important role of support in helping the couple to manage conflict more effectively, explaining that the most important thing during fertility treatment was "support, mainly from both sides. The guy needs to get support, the woman needs to get support, and doctors need to show it" but "if it gets tough emotionally for the couple, not to fight because that just makes things worse."It seemed that Logan advocated that when becoming emotional during treatment, it is important to effectively manage it, and engaging in conflict only amplified the situation.

In summary, Logan depicted how conflict can arise in the couple relationship as treatment-related irritability can result in conflict. Logan's concern that his own internalised emotions would result in an aggressive outburst cautioned him to prevent the conflict howeverpossible, and to deal with his partner's irritability by leaving her alone to calm down. However, this was not an easy task as he was concerned that his partner would misinterpret his distancing as being unsupportive. What is wonderfully demonstrated here, is that these participants recognised their ineffective management style and the role it was playing in increasing their conflict, and their attempts at reducing the conflict through managing their emotions differently. The role of support was an important aspect of their conflict management. Alongside developing coping skills regarding conflict management, couples expressed developing methods to manage their stress during the fertility treatment process.

Stress management as a coping strategy. Participants highlighted various methods that they found useful in their attempts at managing their stress. For some couples, (i) gathering information through independent research helped settle some of their uncertainties. Receiving (ii) support from their partner was also identified as an effective aspect to their coping while others identified (iii) self-regulating activities which assisted in managing their stressful treatment experiences.

Logan explored the need for information to educate himself, in order to circumvent the unexpected as a method to manage treatment-related stress. He shared that, "*I need to know in my life what's going on*. *I don't like surprises*. *I don't like to not know things*. *I need to in my life, I work like this, anything that happens, I need to research*." Lesedi too explored how



conducting independent research assisted her in dealing with a particularly worrying component of treatment, providing her with hope, explaining that "I Googled about it and found that this is not good. They said if the doctor can aspirate it during the egg retrieval, it's a much better option because at least when they do the transfer, that would have been better." Logan and Lesedi demonstrated the importance of independent research in allaying their stressful treatment experiences, as they were able to equip themselves with knowledge, understanding, and options, which provided a sense of predictability in the treatment process, alleviating their stressful experiences.

Logan explained how research became a mutually beneficial activity, as it not only equipped him with knowledge on what to expect with each treatment process, it also enabled him to anticipate what came next, which in turn equipped him with treatment knowledge which he shared with his partner as he educated her about their treatment process, which also assisted her in coping with the treatment process. He shared that, "*I've been through the process from insemination, and I know exactly how many days it takes, how many hours it takes. I've explained it to her, and shown her the videos*" and "*I know right now that we are roundabout day six, so it's time for the egg to implant.*" It seemed that as this participant became increasingly more knowledgeable, he felt more in control of their treatment process and was in a more informed position to create treatment awareness for his partner.

Another aspect of stress management taps into the domain of support. Not only did it assist in reducing conflict, but it alleviated stressful treatment-related experiences for couples. Mieke, upon reflecting on the importance of support in coping with the treatment process, acknowledged that both partners should support one another throughout the entire treatment process. She explained that, "*you can't leave your women or your men alone for one second. You must be there all the time.*" Mieke's experience of the importance of partner support during the treatment process and the ability for that support to alleviate treatment stress, came from her reflections on difficult moments during their treatment process where she felt unsupported by Logan's physical absence and how this impacted her ability to emotionally cope with their treatment at the REU, she "*just cracked one day. Now he's with me all the time and he supports me. Like too much.*" Against that experience, Mieke can "*imagine how they feel going alone through everything.*" Logan agreed with Mieke, adding that supporting your partner is an important facet of the treatment process. Logan seems to demonstrate his support for his



partner, by researching and sourcing treatment-related information as a sign of support, but recognised that although he may research a little too much, some men are just not trying at all, sharing that, "from a guy's side, you need to show her that you care" explaining that, "not all men are the same, they won't go. I mean, I know I'm crazy with all my research, I know that, but other men, to them, there are more important things to do." Logan's research is an expression of support, which he feels may at times be experienced as excessive, but recognises that too much support is better than none at all, which he feels other men are guilty of during treatment. Support seemed to provide couples with a sense of mutual connectedness in their treatment experiences, which assisted couples in coping with the different treatment-related elements they may confront. Participants also shared their resourcefulness in creating self-calming practices to manage their stress during fertility treatment.

Some couples in this study focused on self-calming practices such as focusing on (i) patience, (ii) relaxed thoughts, as well as (iii) self-nurturance, and (iv) reflection. Upon reflecting on the process, Logan identified that focused attention on exercising patience during fertility treatment helped them manage their impatience with the process, sharing that, "*this whole process taught me patience, because you wanna try get things done.*" Logan, on reflecting on what he thinks assisted his partner in coping during the process, isolated "*patience*", especially as it related to the waiting component of treatment (for example, waiting to hear if their pregnancy test results were positive). He shared that, "*everybody's different. For her it's patience all the way. It's a waiting game.*" Mieke highlights the importance for women to remain relaxed during treatment, as the opposite can place strain on the body. Mieke explained that in order to manage treatment-related stress, "*I think the main thing for women to know is just take everything relaxed, don't work your body up.*"

Self-nurturance was a coping skill that did not come easy for some, especially Mieke who explained her surprise when "*I actually started to sing to myself*." Mieke was uncomfortable with singing to herself when she was feeling emotional, as an attempt to feel better, but reported that, "*I just feel like really, you're not a baby, just go on, it's not the end of the world*!"

Some couples focused on lifestyle changes to cope with the stress of treatment. Rozalia reflected on the change in her stress management process, where in the past, she used to emotionally eat to manage stress and now engaged in a healthy lifestyle, where she focused on



a balanced and healthy diet as well as a physical exercise regime. In commenting on past coping methods, she used to "sometimes, you know, the stress made me eat too." Rozalia shared how the fertility treatment process lead to a healthier coping strategy as she "started eating healthy the first day" following visiting the REU. Explaining how she took charge of her health, the next morning "I took everything out. The fish oil, tomato sauce in my cupboard, I threw everything." Rozalia shared her determination, explaining that, "I said that if these things are still in my house, nothing's going to change." Her husband "was looking for a gym by that time for me. I was at work, when I came home from work, he told me 'I found a gym, let's go there.'" Rozalia's exercise regime was "hard at first. We started at the gym training. I started eating healthy. Started eating small portions and I'm thinking it's not like me now. As time goes on, I'm used to that life now. I exercise." Rozalia walked me through how her treating doctor's lifestyle recommendations lead to the development of her coping style throughout the treatment process.

Participants reported reflecting on their treatment process, and the lessons they learned along their treatment path that assisted them in coping. Rozalia reflected on the treatment process as representing a learning opportunity, where "at least there's something I get for going through treatment. At least it shows me that you have to come first, you must eat healthy. I've learnt a lot." Logan referred to treatment as a learning process too, teaching him to accept help and "learning to accept you can't do anything and everything yourself." Lesedi refers to acceptance of the process as a work-in-progress, but tried to embrace the uncertainty of the process as a way to cope as she shared that, "I think maybe we still need to open our mind to the fact that we don't know how it's going to work out, even though it's not easy to just accept that you're trying to be positive."

Drawing a line in the sand when it came to countless experiences of failed treatment attempts seemed like a difficult thing for couples to do. But for some, it was a necessary discussion to have at some point in their treatment process, where the treatment-related pain needed a "fine print" type of clause, allowing couples to mutually explore when they would consider terminating treatment as a method of coping. Rozalia raised this as a way of coping after describing their emotional pain after numerous failed treatments, sharing that, "*Ja, we agreed we are no longer going to try. We will just stay like this.*" Bongani echoed that this was a necessary boundary for the couple in order for them to cope, saying that, "*if we don't pass all what we are doing and maybe my wife doesn't fall pregnant, after that we will be finished with*



all the processes. "Participants experienced a relationship between their treatment outlook and the influence this had on their bodies. With that, they considered how to manage their outlook, to cope with the demands of treatment.

Positive treatment outlook as a coping strategy. Couples, upon identifying their coping strategies, referred to becoming aware of their outlook on treatment, where they intentionally made an effort to remain positive. Mieke's awareness and consequent mindfulness of the relationship between her treatment outlook on the one hand, and the impact she felt this may have had on her body on the other, seems to highlight a conscious effort to remain calm as a way to cope with the stress of treatment, and in so doing, allowed her body to remain calm. Mieke explained that, "the thing is that I don't' want to put my body through negative things. I just wanna keep calm and tell myself 'everything is gonna be okay'." Logan echoed the focused attention on negative thoughts, and considered how to turn that around, sharing that, "I don't want to be negative, don't want to be negative in this place today because it's been a long *journey.*" Although his sharing of experience seemed to highlight that it is difficult to not allow negative thoughts, he does demonstrate that he tried, despite the difficult journey. Refilwe too reiterates the difficulty in trying to keep positive, "Just be positive. It's not easy, but I'm trying," but demonstrates a conscious resolve to do so in an attempt to cope. The awareness of possibilities in coping that these participants arrived at, as well as their willingness to try alternatives, is triumphant as they moved through their fertility treatment processes, trying to manage.

Together with couples identifying the development of coping strategies to manage their stress experiences, participants also identified the social context as shaping their fertility treatment experiences. I conclude the findings chapter now with a discussion on couples' experiences of social contexts that shaped their fertility treatment experiences, and how these systems facilitated, or in some instances, hindered coping for couples during their treatment process.

Experiencing Social Contexts During Fertility Treatment

Participants' fertility treatment experiences extended beyond the borders of their coupleship and were also influenced by various social contexts. Couples shared experiences that drew them closer to, or propelled them further away from their (i) family, (ii) friendship, (iii) work, (iv) community, and (v) spirituality. I first explore each as it related to participants'



joint fertility treatment experiences and I also address their role in assisting or hindering couples in their coping with their fertility treatment.

I begin the discussion by first attending to couples' experiences of their family during fertility treatment, working my way sequentially through the aforementioned systems, and concluding with a discussion on participants' experiences of spirituality during treatment.

Couples' experiences of family during fertility treatment. Participants shared experiencing bitter-sweet familial interactions during treatment. For the couples in this study, fertility treatment permeated beyond the borders of the couple relationship, becoming a systemic issue, either in an overt or in more subtle ways. Couples' experiences of their family system were shaped by their (i) family expectations to grow the family unit and, in some instances, by the expectations that their birth order placed on them to produce offspring. For some couples who did disclose their fertility treatment to their family, the act of sharing (ii) information increased their experiences of connectedness during the treatment experience while others expressed experiencing (iii) judgment regarding their childlessness. As a way of limiting discrimination and judgement, some couples reported that they chose to keep their infertility and their treatment as a (iv) private matter. Conversely, other couples found that their family played an important role in their (v) coping with the stress of fertility treatment.

I explore each of the five findings as it applies to the family system, before moving the discussion to participants' friendships experiences during fertility treatment.

Expectations. Familial expectations to grow the family, created a profound sense of pressure for couples to conceive, since, despite their attempts, they failed to meet the requirements. Mapuleng shared the nature of her family expectations of the couple to produce children, explaining that, "they just say that they want a grandson. If it is your mother, or father, or it can be your other wife, they say they want a child from you." Ashton concurred with Mapuleng's experiences of family expectations to grow the family unit, explaining that, "my parents always wanted us to have a grandkid. For her parents, it was the same thing" and "her parents are expecting a boy because they didn't have a son" where although they have a "son-in-law now, they want a small child in the house and they prefer a boy, but I'm happy with anything. "Zethu shared their parents' desire to actualise grandparenthood before she passes away, explaining that "she wants to see her grandson or daughter before she leaves."



participants' experiences of fertility treatment were shaped by their family expectations to have children. The familial expectation seemed to be driven by growing the family unit as well as for some, to actualise their dream of becoming a grandparent. Connected to this expectation, was the aspect of birth order and how that determined who should be having children and when.

In line with this, some couples addressed the issue of birth order in their family of origin, and how this created additional expectations to bear children. Participants explained how developmental comparisons were made between siblings within their families, and the implications this had for having children. Rozalia shared experiencing the significance of birth order in her family and how this could amplify the expectation to produce children, explaining that the family communicated their expectation to have children by "giving me names. I'm a first born. At my mum's place, there are three of us and already those two have kids." Rozalia continued to elaborate on how the family's expectations to have a child were met with many questions from family members, which was experienced as incredibly painful, leaving the couple feeling like their experiences were not understood. Rozalia shared that, "I'm the oldest one, so you can imagine it's not nice," where her cousins asked, "'Haiwena!' When are you falling pregnant?' 'What's wrong with you?'" and they would "start questioning and questioning" and "those things hurt, but you can't even show them that it's hurting" but sometimes "we answer them. Deep down in our heart you feel like this one is hitting on me." Being questioned communicated the family's expectations that the couple was required to have children. Lebogang shared too that the couple had been directly questioned by the family, who seemed to use the length of their marriage as a yardstick for measuring when it was time to begin growing the family. Lebogang shared that, "we have been married two years now and they are starting to ask a lot of questions. Why?" In some cases, this lead to the avoidance of communicating about fertility treatment with family, so that they would not be met with further questions. Logan shared his wish to avoid communicating about treatment with family, explaining that, "her mom phoned. Everyone's phoning, and you don't wanna talk to them because you don't wanna explain to them because some of them ask us 'so what was the reason?" Participants' experiences of fertility treatment were shaped by family expectations, which amplified their stress as they attempted to grow the family unit.

Although some participants experienced their families as placing expectations on them during their treatment, others felt a sense of connectedness when they shared information regarding their treatment with their families.



Closeness. Couples explored the function of providing information to their family within their couple-family relationships. In some instances, providing information to family was significant as it was seen as a sign of responsibility, importance, and creating a sense of closeness between the family and treatment. Upon reflection with Keketso that it seemed to me that sharing information with their family was important to him, he responded that it is "very, very important. Yes! I'm responsible but there are some people that need to be consulted and informed at the same time, you understand." Keketso's sense of responsibility to share information with family underpinned his disclosure while it was also pivotal to the couple as family assisted them in making treatment-related decisions. Keketso explained that the family asked, "are you really, really sure?" and that's when you start to realise "how far you are when you can say 'okay, I am sure!'" explaining further that "those types of questions you end up saying, you know, okay, I've spoken to them, I told them it's fine and so they have been informed. "Bongani echoed Keketso's sentiments that sharing information has a necessary place within the family, especially as the family takes on an advisory position, where "the mother and father can advise you in terms of children, when you grow, you know. "Couples who shared with their families that they are undergoing fertility treatment shared that this was driven by a sense of responsibility to do so, on the one hand, and by the advisory role that families held.

Information sharing was significant as the result was a sense of a connectedness between the family and the treatment experience. Logan explained how his "brother wanted to know"asking"show me a video"because"I don't understand what you are saying, so show me."So, he went "on YouTube to show him a couple of videos, her sister as well, and now they understand and they sympathise with her."Others described experiencing family as curious, and very much part of their treatment process, where they too would experience and express emotional responses to the couples' treatment, such as anxiety, excitement, and others adopting a cautiously optimistic approach to treatment. In answering a question related to the family's anxiety levels, Mieke highlighted that their anxiety is higher than the couple's as "they are worse, yoh" and Logan agreed that "Ja, they are worse than me, a lot worse than me." It seems that some participants experienced their families as invested in their treatment process which created a sense of connectedness. Some couples in this study, however, did not always experience a sense of connectedness and shared their painful discrimination experiences within the family system.



Judgement. Some participants expressed experiencing discrimination and prejudice within the family as a result of their childlessness. Prejudicial experiences extended beyond the confines of gender, where both men and women in this study shared their encounters with me. Zethu highlighted her personal experiences of discrimination, saying that, "even your family can discriminate against you sometimes. But it starts with your in-laws because usually after you are married, they want their grandchildren, so it will start there." Here, this participant experienced discrimination from both families, beginning with her in-laws, as a result of their childlessness. However, some couples experienced family members as assigning a scapegoat to the couples' infertility by implicating the female partner as the reason for their infertility. Zethu continued to share her prejudicial experiences with me and explained how the family assigned her as having the fertility problem and therefore, the reason for the couple's involuntary childlessness. She explains the ridicule that accompanied the family's interactions with her as a result of the couple's infertility, and shared that because "you are a woman and you can't have children, they will call you names. "Logan too shared their personal experiences of family who understood the infertility as Mieke's fault, which angered him, explaining that what "made me angry is that some people said it's because of her" and because she's "working at the school, she's running around, picking up kids. It's her, and it made it worse, because I mean, you can't say that to her." In sharing the couple's experiences, it seems Logan made sense of their family's judgemental comments as blaming his partner for their childlessness. Participants, both men and women, shared their experiences of discrimination within the family system. Discrimination shows up again in each of the subsequent social contexts that I address in this chapter. Perhaps this is one of the salient reasons that contributed to couples choosing to keep their infertility and their treatment a private matter. As with each system, I explore the issue of privacy regarding treatment, exploring how it took shape in these participants' family relationships.

Privacy. This was a significant aspect of couples' fertility treatment experiences within different contexts, and the family context was no exception. Some couples who chose to not openly disclose their engagement in fertility treatment was framed by their fear of experiencing prejudice. The question that arose either implicitly or explicitly during the interview process was regarding who the couples had shared their fertility treatment-seeking with. After being asked this question, Zethu, replied in a matter of fact manner, simply stating: "*Ah, no one!*" Her response as it stands short, sharp, and to the point, was a stark realisation that the couple experienced the treatment process entirely alone. As I digested that realisation, in light of the



findings of this study up until this point, I wondered how that was possible. How did they cope with the demands of treatment on their own? This was not an isolated case. Other participants shared that they too kept their fertility treatment as a private couple issue. Lesedi and Graeme shared that they too preferred not disclosing their treatment-seeking with family. Lesedi's giggles, as well as the manner in which she shared their experiences, left me with the sense that she was ill at ease with their choice of nondisclosure, giggling that "unfortunately our parents don't know about it." Lesedi explored their choice for nondisclosure as shaped by her perception that their families would not understand, saying that, "they don't know the things that we go through every day, the things that we experience." She shared the pragmatic and emotional difficulties in keeping their treatment as a private issue. Lesedi referred to the difficulty as it applied to her sibling relationship, as privacy contradicted the closeness they shared in their relationship, sharing, "like I told you, no-one knows. It's only me and Graeme that knows about this. You know now." Against the backdrop of only her and her husband, and now me as the researcher knowing, she sketches the importance of this private information against the importance of her sibling relationship, sharing that, "we are very close, me and my sister. I'm light skinned so some of these things you can start seeing on my tummy, and she's like, 'why are you like this?'" In an attempt to keep their treatment private, she explained to her sister that, "No man, it's the hot water bottle, or maybe the plugs? But it has been a very mixed feeling journey." This seemed to highlight a redefining element to infertility treatment experiences as they applied to family relationships, changing communication in an unwanted manner. Lebogang explained their choice for non-disclosure as being informed by their culture, which they experienced as inhibiting the family from fully understanding their choice to access western medicine. Lebogang shared that, "No, we don't tell people. We keep it to ourselves. You know us black people, man. It's not like you guys...us, you... oh, it's too much for us!" continuing to elaborate, Lebogang explains that, "like, black people will discourage you. They don't believe in this medication and things." This is a precarious position for a couple to be in, where involuntary childlessness is experienced through a cultural lens which does not condone the use of western medicine. In this case, their family's adherence to cultural norms contributed to the couple's incognito fertility treatment, where they chose to secretly access treatment to avoid the family's norm-related input.

For those couples who shared their active involvement in fertility treatment with their families, some participants shared experiencing it as a positive experience, which assisted in facilitating coping.



Coping. Some participants expressed experiencing their family as supportive during times where they discussed the family's history of infertility. As they discussed their infertility history, it seemed to (i) normalise their treatment process. Family also illustrated their support through (ii) praying for the couple, and messaging words of support, as well as through displaying (iii) curiosity regarding their treatment when they requested additional information regarding the couple's treatment.

Mieke shared how her family's history of overcoming infertility helped her to cope, as she explained that, "I recently found out that one of my Ouma's sisters went for IVF also, and she's got three children." Mieke's grandmother, in sharing this information, normalised the process for her, helping her to cope a little better with it. Mieke explained, "so, I'm like, okay, at least I'm not the only one in the family that went through it", feeling less alone in her experiences of infertility. Logan shared his positive experiences of the numerous gestures of support received from family when "I mean, we got a great support system! Everybody's praying today, and have been SMS-ing and Facebooking and just going crazy." Explaining that the family "from both sides, everyone's phoning you, 'good luck for tomorrow'." Family expressed their support further by requesting treatment-related information, where "especially my brother and her sister, they want to know more, because to them, they also feel like they've learnt something "and now they know "exactly where we are in the journey. So, they have been SMS-ing us 'listen, so you guys gonna do this? Today's day three, so it's probably gonna be today, or it's half way', so they know more" which seemed to help the couple feel that their families were more closely connected to their treatment process, which they experienced as supportive. Bongani concurred with Logan's experience of support, as he made reference to his family supportively monitoring their journey, as they "know all the steps we took. They are behind us on that." Bongani and Logan's experiences seem to highlight that with knowing more, families may be in a better position to support couples.

I now turn to another social context which shaped couples' fertility treatment experiences: Friendship.

Couple's experiences of friendship during fertility treatment. For those couples who chose to disclose their fertility treatment experiences with their friends, they expressed a general feeling that their friends (i) lacked authentic understanding of their fertility difficulties and treatment seeking experiences. As a result, some participants elected to adopt an (ii) avoidant communication style when it came to their treatment experiences, in an attempt to manage their



frustrations. On the other hand, some participants experienced the surprising (iii) development of new friendships within the REU. Here, couples expressed feeling a sense of mutual understanding and connectedness through shared fertility treatment experiences with fellow patients. I attend to the dichotomous experiences below, by first addressing participants' experiences of friendships outside of the treatment setting, where they expressed experiencing their friendships as lacking understanding, resulting in a breakdown in communication. This is then followed by a discussion on the positive experience of the development of in-treatment relationships.

Lack of understanding. Logan explained how friends struggled to fully comprehend their treatment experiences, even after the couple shared information, leaving the couple with a sense that friends became lost; "sometimes you do explain what IVF is. It's once you start explaining, and once you get to that point, that they don't understand." Another example that participants shared of friends not fully understanding their fertility treatment experiences, were times where friends would provide misguided advice. This was interpreted as insulting and patronising, creating the perception that their friends did not fully understand their fertility dilemma. Logan illustrated their experience of friends not understanding the breadth of their infertility process, which seemed to create a sense of emotional distance in the couple's friendships. Logan shared that, "people don't understand. Many of them, many of them, most of them!" although "I understand why, because they don't know my background, so they think everything is normal, so then I leave it" however, this is a difficult task when it comes to "friends that do know. I said to them 'you know, is the baby gonna come crawl up her leg?' I mean you can't just leave it naturally to happen, and then they said, 'oh, sorry, we forgot about you'." Recommendations to let nature take its course seemed to highlight for the couple their unconventional treatment experiences (in that Logan is transgender and cannot father his own children) and amplified the couple's frustration with not being fully understood, and with that, their frustration with their misinformed advice-giving. Mieke shared the intensity of emotions the couple felt when friends provided words of encouragement. Mieke shared an example where a friend advised the couple not to "worry. Trust. Just trust in God. I mean, I do!" or they say, "'Ah, you'll get there. If it's not meant to be now, then...' I'm like 'you better just shh, because I will sommer hit you with a fist!" Mieke's example highlighted the frustration and anger she experienced in response to her friends' advice. Logan shared that some friends, in light of their fertility struggle, suggested that the couple adopts a child. He shared that his "one friend said the other day that God put people like us on earth to look after kids that need to be



adopted." He experienced his friend's comment as offensive, judgemental, and insensitive in sharing his experiences of their friends not fully understanding their treatment experiences. It seems that when participants felt a sense of emotional disconnect due to a lack of perceived understanding, some participants then assumed an avoidant communication style, where they made a conscious effort to not talk about fertility treatment.

Avoidant communication. It seemed that when participants did not feel understood, some adopted an avoidant communication style in their friendships. Here couples attempted to avoid talking about their fertility treatment experiences with their friends which was experienced as challenging at times as their non-communication had the potential to sell them out, highlighting more overtly than intended, the fertility treatment process that they wished to avoid talking about. Logan shared his strategy, where "we've been having friends over for dinner and everybody asks her or me, 'what's wrong? Why are you so quiet? Why are you so far away?" They "don't understand. We tell them we just stressing about this IVF, but everybody is asking." Participants experienced their friends' concern regarding the withdrawal they experienced in the friendship, but in their attempts at trying to understand it better, they seemed to communicate their lack of understanding further. Logan explains that *they "will ask* 'what's wrong with Mieke? Did you guys have a fight?' Which I hate because I mean, why would we fight? They don't get the fact that what we are going through is so much." The rationale given by friends seems to further convey to couples that they lack treatment-related insight. However, the friendship story is not all doom and gloom, where couples shared that they made new friends in the treatment process.

New friendships. A positive experience that came out of fertility treatment seeking was the development of new friendships in the process. It was in these new friendships that couples shared feeling a sense of shared connectedness in their fertility treatment experiences. Lesedi shared that a pleasant consequence of fertility treatment was the development of friendships with other patients at the REU. Here she shared that, *"the nice thing about this process is that I have made new friends."* Mieke concurred with Lesedi's positive experience of making new in-treatment friends, and adds that she experienced a sense of shared connectedness, which facilitated a deep sense of understanding. She explained that, *"no one really understands but now we are talking to someone else, and because she is going through it, she feels the same way."* Friendships that developed as a result of their treatment seemed to create a sense of understanding and connectedness for participants in this study.



In summary, participants expressed dichotomous friendship experiences. Here, participants shared (i) feeling that their friends did not fully understand their treatment experiences, which resulted in an attempt to (ii) avoid communicating about their treatment experiences. But on the other hand, participants experienced the unexpected (iii) development of friendships within the REU, where a feeling of understanding and connectedness through shared fertility treatment experiences was encountered.

Although participants who chose to disclose their treatment experiences with their friends did not always feel fully understood, some couples did experience some of their friendships as helpful in their coping with treatment.

Coping. As I discuss the participants' experiences of friends here, I refer to a sense of friendship in the contexts in which they arose and how these friendships facilitated coping. Either in-person or online experiences of friendship provided participants with a much-needed sense of support.

Remembering that for many of the couples, no one knew about their treatment process, as they preferred to keep it a private matter between the couple. A way around this was to access support online. Some couples developed friendships during the process, which seemed like an unintended consequence of the treatment process. Lesedi in highlighted the friendships that were made during the couple's fertility treatment, explained how the women she had befriended shared their treatment-related experiences with each other, as they would "*call each other to say, 'how is this medication treating you? I'm feeling like this, is this normal?'*" and "*we follow up with each other to say, 'when are you going in for your ovitral?' When is the transfer?'*" Monitoring and normalising the treatment process for each other was helpful for participants as they assisted each other to cope through providing support to those who were going through the process as well. Lesedi shared that, "*it's nice because if you talk to people who are experiencing the same thing as you, you don't have to explain as you do to somebody who doesn't even understand.*" In exploring the significance of these relationships, she highlighted the experience of connectedness through mutual understanding and a sense of shared experience.

Online support groups provided couples with additional options for accessing support. Logan highlights how online support groups for men provided men with the opportunity to



share how they were feeling and provided supportive ideas on how to manage their emotions. Logan shared his experiences where, "I've seen many men on the support groups and on the internet, that's been crying. They asking: 'What can I do? I'm frustrated, I can't think at work, I feel like I can kill people at my work'"and "most of the guys would say, 'Just cry. Just go out in the bush or the veld or go fishing." Men embraced their own and others' emotional reactions to the treatment process, and provided an empathic space for coping. Logan expressed how the online community provided additional information based on their experiences, which seemed to help them cope with treatment-related uncertainty, explaining that, "I went on the internet and some people said, 'you know what, I had my normal period for nine months', and it gives you hope as you are trying to get hope from a situation."

Men were not the only ones who accessed online support. Mieke highlighted the simplicity and accessibility of online forums, sharing that, "the groups where woman talk, you just type in like 'I went through IVF' and it throws like a lot of things out and then women just talk," explaining that "it's just nice to read that this one's going through this, and this one went through that. You can relate, like 'wow this is me'." Mieke experienced online groups and forums as an easily accessible, supportive experience, which normalised her treatment experiences.

In addition to the friendship system, couples' fertility treatment experiences were also shaped by their experiences of the workplace. I discuss the work context next, in creating additional insight into the aspects that shaped couples' treatment experiences.

Couples' experiences of work during fertility treatment. When I first reflected on the interplay between couples' treatment experiences and the work context, the salient experience that I presumed would be shared was the pragmatic difficulties treatment created in the work environment in respect of interrupting their work schedules. While this was indeed a finding, what I never considered was that some participants experienced work as an environment which represented a developmental benchmark, used to measure one's own development.

Personal development. A sense of personal success was not only measured by career development for participants, but was measured against reaching the developmental milestones of their colleagues who were having children. Here, judgement and abnormality became part



of their treatment experiences. Work created stressful, painful, pressurising treatment experiences, which elicited increased irritability for couples, and in some instances increased conflict in the workplace.

Work was experienced as a context for measuring successful achievement of developmental milestones. Success was not only related to academic and career development, but was measured against reaching the developmental milestone of having children. Lesedi's fertility treatment experiences were shaped by a sense of abnormality in the workplace, sharing that, *"it's mostly at work. The department that I work in is a very young, youthful generation, who are mostly studying to go up and are successful* "where her colleagues are "getting married and sometimes things unfold for other people" and where they just seem to "get married, buy a house, and then have kids, so everything seems normal for them."So, for them "when it's two years down the line, they start making funny comments, like 'when are you having a baby?' or indirectly. "Sometimes, "Somebody will probably come with their kids' donation form from school, from crèche or something, and say 'this is what we parents do, my kids are involved in activities' you know, "sharing that "you can sense that it's somebody trying to tell you that, you know, you are not normal, you know, so we both get that from the kind of surroundings we involved in." Here, her fertility treatment experiences were shaped by judgement and abnormality in the workplace.

Work not only impacted participants' sense of achieving personal success both in the workplace and in their personal lives, it also related to the difficulty that came with managing the expectations in the triad of work, fertility treatment, and the couple relationship.

*Clashes.*On exploring couples' treatment experiences as it related to the work context, there was the obvious dilemma it posed to juggling work and treatment-related expectations. Mieke illustrated the disruption that fertility treatment presented to managing her work schedule, which created not only conflict within the work environment, but also within the couple's relationship: "at work I feel like I am doing whatever I want to." While referring to her partner's boss (who is also his father), she explains that, "I can understand your father's point, but the thing is, I take off twice a week or whatever. He must only come on certain days like this." Expanding on the impact that treatment has on her work schedule further, she explains that, "I get frustrated because I'm saying like, 'why can't he take off?' On Monday I needed him, but then he wasn't here." Here, Mieke explained how fertility treatment impacted



her work schedule, resulting in absenteeism and with that, the frustration that it impacts her schedule more so than her partner's. This not only introduced an additional element of frustration in their relationship as she felt she took more time off work than he did, but she also seemed to experience Logan's occasional absenteeism as disappointing, as she required his support throughout treatment. Mieke explored the cumulative impact of fertility treatment: first absenteeism due to treatment, and second, the impact of the side effects of medication on the treated partner's capacity to work optimally. This seemed to bring with it a personal work ethic dilemma, as she did not want treatment to further impact her ability to perform at work, stating that, *"Yesterday, I was so sick at work that I couldn't walk."* Feeling frustrated with herself, she shared that, *"I said 'stop, you gonna do this!"* because *"I can't take off work. I could be dead but I can't take off now. I'm not going to take off because I'm off like forever in the current year"* so *"even though I'm sick, I'm sick, I'm sick, but I will go to work, I will not stay at home."* Mieke demonstrates that fertility treatment not only affects work as it related to absenteeism due to treatment time at the REU, but also due to side effects of the treatment.

The stress of infertility treatment impacted her capacity to deal with work-related demands, which she experienced as stressful during the treatment process. For Mieke, she considered how she could make her work environment more manageable during her treatment. She related that, "*I scream a lot! Like, the whole day, I work myself up, like, from my stomach.*" She explains her demanding work as a teacher where she has "...*forty kids. It's a lot and I really do think that's why I'm looking for another job.*" Explaining an opportunity to have less challenging working conditions, she explained that, "*I did get this lady who said there's also a grade R job with fourteen pupils. From forty to fourteen, so I'm gonna take off.*" This participant's experience, in particular, highlighted the demands that fertility treatment places on a person's capacity to cope with responsibilities that run concurrently with their treatment, such as those placed by work.

The couples' work-related responsibilities were at times at odds with in-treatmentrelated expectations within the couple system. In order to attend consultations, for example, a couple may need to be prepared for it to happen during working hours. Depending on the work context, couples may find this a difficult element to manage and accommodate. This may have a negative impact on the couple, should one of the partners be able to attend consultations or treatment, where the other cannot avail themselves for presence at treatment. Logan explained this difficulty in sharing that, *"she's got a boss that understands, where my dad doesn't because*



he was in Durban, so I had to run everything here." Explaining the difficulty further "I can't leave it and just go, I mean this is the most important thing in my life, but how am I supposed to do this if I don't have a job?"

Logan highlighted the conflict he faced in trying to juggle his work-related responsibilities, his partner-related responsibilities, and at the same time to take care of himself as a partner in the treatment process. He shared that, "you have got the phone ringing, because I'm trying to run a business, and then my dad's phoning because he is trying to run a business, and I mean, I'm there for her, and for me." Managing these responsibilities whilst engaging in fertility treatment, expressed that treatment is stressful. In highlighting the dual context conflict that treatment created, Logan shared how he perceived his partner's work environment as placing less pressure on her in comparison to his work-related pressure imposed by his boss. He explained that he experiences his partner's boss as "fine, and so are the other people working there, because she's basically friends with all of them, so she's fine", however, "with me and my dad, we had a fight on Monday because he thinks that this whole IVF thing is taking over his business." Participants' experiences of fertility treatment were shaped by the collision between work- and treatment-related commitments, which negatively impacted the couple relationship by introducing an additional strain on the relationship during the treatment process.

Participants shared that work in some instances, was experienced as judgemental in respect of their fertility treatment process.

Judgement. Work, for one of the participants, became a place of prejudice and judgement. In working at a hospital, she asked if one of the doctors could examine her as she wanted to get closer to understanding the couple's fertility difficulties. Work became a context for ridicule, judgement and assumptions, which were experienced as a painful part of her fertility treatment investigation. Rozalia shared her painful experiences, saying that, "*I was at the hospital where I worked and there are doctors working there, so the PA asked the doctor to check me to see what's happening with me*" because "*I told the PA that I have a problem, and she said, 'No, I'll ask the doctor to check you' and then the doctor agreed to check me*" explaining that after the doctor examined her "*she said to me 'Oh, but I don't see anything'. She talked to me, then she went to the lady that admits you and she was asking the lady 'Was she doing an abortion or an operation?*" Rozalia described how she "*was gossiping. She's a doctor, and she saw a problem with me, and she's not even reporting that to me, she's reporting*



it to another person about me." She shared further that, "I had an operation when I was at school. 'What was the operation for? Did you make an abortion?' It was painful for me, where I asked, 'Why is this doctor doing this to me?" Although this was an isolated incident reported during the interview process, it illustrated a painful example of work- and treatment-related judgement, where assumptions and the manner in which those assumptions were managed, were experienced as prejudicial. I remember as I document the findings here, how Rozalia shared this experience towards the latter part of the first interview. The experiences that Rozalia shared about her first fertility investigation left me with a profound sense of respect. Not only because she demonstrated an ability to rise above the prejudicial experience, as it is depicted here in isolation, but reaffirmed and accented the importance of each person's individual experiences, no matter what they may be or how they may present to me. Whether personal experiences are being shared in a therapeutic or personal context, I have always viewed people's experiences as unique, no matter the common threads that may seem to weave experiences together, creating similarities. I suppose that is what I found most challenging about writing the findings, as I was required to tell the story that was common to the participants' experiences of fertility treatment in this study, but at the same time, wanted to capture the voice of the teller. Not feeling understood or feeling a sense of judgement can inhibit the teller from doing just that, which the participants echoed in this study.

Privacy. Some couples chose to keep their fertility treatment private, which posed as particularly difficult. Participants experienced the workplace as shaping their experiences of fertility treatment. Participants' work context represented a place for making social comparisons with their colleagues regarding their achievement of (i) developmental success. Couples expressed experiencing a clash between work- and treatment-related commitments, where the development of a (iii) triad between work, treatment, and relationship responsibilities arose, as the management of all three was not always entirely possible. A participant shared experiencing a (iv) judgemental work-treatment-related encounter, which negatively shaped her initial fertility investigation. Examples like this may represent one of the many reasons for informing the participants' reason for maintaining (v) privacy.

Maintaining treatment privacy whilst holding down employment was a challenge, especially when required to administer injections during working hours, paired with the fear of their secret fertility treatment being discovered. Lesedi goes into detail as she explored the significance of the strain of treatment in the context of work as it related to privacy, and how



her body threatened to disclose their incognito treatment when "I had to do it at work because it was at four o'clock and I knock off at half past four" explaining that it "was also straining because you don't want your colleagues to see you out and about and jumping around with all this medication". Explaining that, "having to keep that as a secret, you know, you feel like everybody's looking at you but they are." Lesedi shared that, "at first it was okay, but then as time went, you know, you don't have space anymore in your tummy, you know, and sometimes the blood comes out and you wonder if you did it correctly or not." Lesedi shared that luckily for her, the injections "never made me feel sick or anything. The only problem for me was my tummy was swollen." In sharing her experiences, Lesedi explains how keeping their fertility treatment as a secret was a tall order as the treatment process increasingly placed demands on her, leading to injections which needed to be administered while she was still at work. This made it challenging for her to maintain their privacy as the injections and her stomach, in response to the injections, threatened to sell her out at work. Very few of the participants who were employed, shared with their employer or work colleagues that they were receiving fertility treatment as they wished to keep their treatment private.

Coping. For one of the couples that did share that they were receiving fertility treatment, they experienced work as supportive during their treatment process. Although trying at times, Mieke and Logan explained the significance of an understanding work environment, in the treatment process. Mieke expressed the support she received when treatment interfered with her work, explaining that, "*I have to explain to my boss the whole time 'the next step is this, and the next step is that', and she's like, the whole time, 'Mieke relax, okay! I get it.*" Mieke experienced her work environment as accommodating her need for treatment-related time off. In sharing the support Mieke received at work when she was too emotional to fulfil her job function, Logan shared the importance of her work environment's empathic support during their process, saying that, "*everybody at work is saying 'no, it's fine. Don't worry'.*" Although the findings of this study do not speak volumes to the supportive function that the work context can play, it did support at least one couple for the duration of their treatment process.

In summary, couples' experiences of their fertility treatment were shaped by the work context. Work was experienced as a place for making social comparisons with their colleagues regarding their (i) developmental success. Couples experienced a clash between work- and treatment-related commitments, where a (iii) triad developed between work, treatment, and relationship responsibilities, as the juggling of all three was not always easily attained. A



participant shared (iv) judgemental work-treatment-related experiences, which negatively shaped her initial fertility investigations; perhaps one of the many reasons that informed the participants' (v) privacy. Not all participants chose to keep their fertility treatment private, with one couple experiencing their work environment as (vi) facilitating coping.

I turn now to couples' shared experiences of their community as it related to their treatment experiences and coping.

Couples' experiences of community during fertility treatment. The adage "it takes a village to raise a child", seems congruent with a pronatalist community that values having children. When this is turned on its head, what happens to that "village" when there are no children? How do communities view the couple without a child? How do couples experience their community in the midst of their fertility treatment process? Couples reported arduous community experiences during fertility treatment as it (i) placed expectations on couples to grow the family unit. Couples expressed experiencing their community as (ii) probing and (iii) judgmental as it related to their involuntary childlessness.

Expectations. The findings indicated that couples experienced their community as placing an undisputable expectation to grow their family unit. Herein lay the difficulty as couples faced involuntary childlessness against the backdrop of pronatalist societal expectations. George shared their experiences in beginning to illustrate the views of their community, explaining that, "Our culture says if someone gets married, the first thing he or she must think of is having a child." Mapuleng elaborated further on this experience, after I asked, "So, if you don't have children, what happens then?" She shared their experience of discrimination as a result of childlessness, sharing that, "Uh, they start talking" stating that, "everyone in the village talks about you."

Zethu, in expressing the value children hold in the community, coldly demonstrated the worthlessness couples felt when faced with infertility, sharing that, *"you're nothing if you got no children."* For some, large families are experienced as a community requirement, and the experience of this in the absence of children coupled with their fertility treatment, made for a challenging treatment experience. Mapuleng, in sharing their experiences of their community's pronatalism, explained that bearing children is a community expectation required from a young age. In sharing her experiences of community views on age, marriage and childbearing, it



seemed to provide insight into their difficulty, where she expressed, "*I think it's funny because* everyone in our village you see, maybe when someone gets married at the age of 18, they know that she must be having five or more children. "Sipho concurred with Mapuleng, explaining that having a big family is a community expectation as they "believe in big families."In some instances, the expectation to have a big family lead to community members questioning the couple about why that expectation had not been met within a certain time frame.

Probing. Two of the couples expressed experiencing their communities as probing throughout their fertility treatment, as they noted that these couples were not fulfilling the community expectation to grow the family unit. Lebogang expressed an urgency and pressure that came with not having children while being expected to. She shared that, "we been married two years now, they starting to ask a lot of questions, 'why?'." Community probing extended to the choices couples made regarding their treatment-related decisions. Logan illustrated the judgmental community questions in respect of treatment costs, as he shared "the thing is that we get frustrated because people ask us 'why would you ever wanna put so much money down for this, for a kid?'." Community questions were experienced as judgemental and left the couple feeling frustrated.

Judgement. Women, in particular, shared experiencing their communities as judgmental and in some instances as discriminatory as it related to their fertility treatment experiences. Zethu shared her experiences of judgement and discriminationin saying that, "if you are a woman, and you can't have children, they will call you names." Communities were experienced as assigning blame for couples' childlessness to the female partner, who in Zethu's case, was viewed as barren. Zethu shared that, "people are looking at me and that's the problem because they say 'she's a barren. She can't have children' while I know that I can and that's the problem now." As I closely track women's community experiences, the story unfolded where women were implicated as being the cause of the couple's infertility. In these instances, women were viewed as ultimately responsible for the problem, and were, therefore, required to take responsibility for the solution. Keketso shared how the community viewed the role of the female partner in the couple's decision-making, understanding it as the female as being responsible for reproductive decisions as she "might be seen as responsible for the decision." Men, on the other hand, experienced feeling a sense of accountability and responsibility for directing the couple regarding treatment. Keketso explained the impact of community expectations on the role of the male partner to take charge of their treatment-related decision-



making, sharing that, "what I'm saying in terms of accountability and responsibility is that the vast amount of the decision lies with me, not with her" adding that, "the culture says that I have to be accountable for the decision."

Men too shared experiencing their community as discriminating against them, where they encountered name calling, gossiping, and were faced with numerous questions regarding the couple's childlessness. Bernard, in sharing his experience of prejudice, demonstrated that the community shows an accepting façade, while talking about him when he is not in their presence, which inhibits his interactions with community members since "they will pretend to you and other people. They pretend like it's okay but if you turn your back, they call you names." Ashton's experiences of a judgmental community created distrust, which seemed to inform the couple's choice to keep their treatment private. He explained that, "people's eyes are very bad. Some people dislike you and they don't want you to fall pregnant, or to succeed in life" explaining further that, "when we come here, people ask 'where are you going so early in the morning?' as we leave the house at half past five and we say that we just going out" or that "we dropping someone off at the airport, and then we'll come back and we don't mention where we going" because "I don't like people to know what I'm up to. Why must they know that we had to go for IUI or IVF to get a child? Why couldn't we conceive on our own? So, I feel it's no one's business." Being a member of a community that prizes children is painful and gave me more insight into the depths of treatment-related experiences. As I considered the saturation of the couple in a community that values procreation, the difficulty for the couple in treatment is amplified by their community context. So, what about coping then?

Coping. The community context was experienced as placing expectations, as probing, and as judgemental and prejudicial of the childless couples in this study. But surely this cannot be the only community experiences of involuntary childlessness? Surely not? While I concede that this finding can be in part, a reflection of a small sample, and may not be generalised to the South African population, it was a finding of this study nevertheless. It got me wondering further about the implications of not one of the research participants sharing positive community in assisting the couple in their coping with their infertility. Does this point towards an experience of stigma in communities where childlessness is associated with judgement from community members, which therefore enables a silencing process (i.e. privacy)? The absence of community in the research data got me wondering about the potential for pockets of



communities to have been of potential help to some participants, but were never given the chance? Also, if there is a pervasive misunderstanding in communities around childlessness, what could be done to educate community members about infertility, moving away from a narrow reproductive health model which may centre mostly on one aspect (i.e. to prevent pregnancies in disadvantaged communities).

The untold community story has left me with a number of questions. The first aspect is that I feel I "dropped the ball" in not hearing this untold story during the time of the interviewing process. The second is that it has left me with a number of questions regarding how participants experienced their community in respect of coping per se. In other words, how am I to interpret participants not mentioning their community at all in this regard? Unfortunately, as it pertains to this research study, I will never know, but I hope that in the future, more can be sourced about the community, so that gaps can be identified and improved upon, so that couples can be provided the option of an additional support structure should they wish to utilise it.

Couples, as members of their pronatalist communities, are faced with enduring fertility treatment against the backdrop of stigma, prejudice, blame, and feeling a sense that they are developmentally stunted. It is no wonder then, in the absence of community support, that many chose to access or conversely, disconnect from their spiritual beliefs.

Couples' experiences of spirituality during fertility treatment. Participants' shared experiencing dominant religious views that advocated (i) growing the family unit and that in some instances, questioned the appropriateness of (ii) utilising fertility treatment. Couples' spiritual experiences during fertility treatment were not only punctuated by a spiritual dilemma, where for some participants, they felt a sense of deepened spiritual (iii) connectedness. I begin by exploring the first of the three spiritual findings as it applied to participants' experiences of fertility treatment.

Expectations. Couples shared that their religion or spiritual belief systems placed value on bearing children. Against the spiritual view that children were considered as blessings, the dilemma lies for those who are religious and cannot bear children. Lesedi explained against the backdrop of her Christian spiritual beliefs that, *"when you are a Christian, even the Bible talks about having faith, believing that one day God will bless you. So, for us, it's also the same thing that you believe."* She explained that, *"my husband is more on the side of saying that you must*



have faith. One day it's gonna happen" but then "you know, as a woman in this society, it kind of puts a lot of pressure on you. But we ended up both agreeing to go and doing this." It seemed that for this couple, they felt conflicted by having faith that they will fall pregnant on the one hand, alongside societal pressure and urgency to conceive on the other hand.

Participants shared experiences where their spiritual beliefs and religious doctrines disapproved of utilising fertility treatment, and the dilemma this presented in the light of their involuntary childlessness.

Disapproval. For some couples, religious doctrine was experienced as disapproving of fertility treatment-seeking, which had a significant impact for couples when undergoing treatment. Lesedi and Graeme, who described themselves as devoted church-goers, asked that their church's identity remained anonymous as they did not want any chance for their church to discover that they were engaging in treatment. It seemed as though they were living two lives: a religious life and an incognito infertile life. Lesedi requested, "please don't mention our church in terms of this because like I said, it's something that is not supposed to have been something that we do, it's just something that is a preference for us." This created difficulty for this couple, as these participants, in particular, described how their daily lives were guided by their religious values, and not by cultural norms. Lesedi illustrated this in sharing that, "We don't necessarily follow our culture, like your African cultural base, so most of our day-to-day, or how we do things, is mostly structured around our religion." The conundrum that living both a spiritual life at the same time as a fertility treated life presented for couples was not experienced as a straightforward task to manage. However, Lesedi and Graeme seemed to try to strike a balance by living a life that was guided by their spiritual beliefs, whilst having one pocket that they chose to do differently.

Not all participants endured a conflicted spiritual experience during their fertility treatment, with some feeling a deep sense of spiritual connectedness during their treatment.

Connectedness. Others felt a sense of comfort through their spiritual connectedness, as religion guided their daily lives and became a significant aspect of their treatment process. Some couples increased prayers, where Ashton explained that "we as Muslims have got to pray five times a day and with this whole procedure, we have been praying a lot over the past few months, so hopefully everything goes well." Ashton, from a Muslim background, placed



importance on prayer as an important aspect that ran parallel to their fertility treatment process. Couples tended to increase their reading of spiritual material throughout treatment, which illustrated a further connectedness to their spirituality. Ashton explained that, "we have been praying a lot and we read the Quran, that's our Holy Bible." Couples explored how they accessed their Being for help through prayer. Bongiexplained that, "I think God will help. God will help. You need to pray very hard and you will come right." Although some participants' spiritual experiences were shaped by their experiences of disapproval and for others a sense of connectedness, some couples reported experiencing spirituality as facilitating their coping.

Coping. Spiritual support was accessed and came in varying forms. For some couples, they found strength and hope through prayer and increased scripture readings. For others, it was through turning to their Being in contemplation or prayer. While others looked for and made sense of external signs in their environment as spiritual signs from their Being, giving them a sense of hope that all would turn out alright.

Logan, in explaining his need to be alone to process his feelings, was reminded of his spiritual beliefs, which lead him to turn to his God. Logan shared that, "I wanted to be alone. Then I thought 'why?' I mean, me myself and her, we have a good relationship with the Lord, with God, so I thought you know what, let me go and sit with Him." It was in quiet contemplation that he reconnected with his spirituality as he attempted to cope with the difficulty of fertility treatment. He further shared the couple's move towards spirituality as a way of coping during the treatment process, as "we have been talking a lot to Him lately." Lesedi shared how their Christian faith and beliefs provided the couple with hope as they endured their treatment process, sharing that, "when you are a Christian, the Bible talks about having faith, believing that one day God will bless you "so for us "it's also the same thing that you believe. My husband is more on the side of saying that you know, 'Have faith. One day it's gonna happen'." Lesedi's account explained how although she has faith, she experienced Graeme's beliefs as a little stronger than hers at times. Bongani placed faith in his God to direct a successful process, which seemed to help him cope with the uncertainty of the treatment process. He shared that "I think the Mighty won't allow that to happen and everything will be fine. That belief of saying things will be fine, and that we are going to finish and end the story, and have the baby and that's it." Bongani echoed Graeme's resolve to place hope and trust in his God, and in so doing, it helped him to cope with the process as he places "hope and trust that God will help us to go through this."



Other participants shared accessing religious leaders for support and guidance, in respect of counsel and on prayer, which assisted them to cope during treatment. Ashton, when asked if he accessed religious support during treatment, shared that "we have ja. We have gone to see a few, like priests, for example we go see "who" tell us what to pray so that everything goes well, like a prayer to help you cope and stuff like that "we have "been seeing a few people just to give us what to read so that everything goes well and you know, they must pray for us as well."Ashton, a practising Muslim, explained in a manner that was relatable to me, by using the term "priest" in reference to the religious figures he and his partner spoke to regarding their treatment experiences. Here, Ashton makes sense of his spiritual experience as a mutual exchange of accessing support and guidance, whilst receiving support through prayers said for the couple. In asking Mieke and Logan how they were going to get through their treatment process, Mieke summed up their coping strategy as simply: "Well now it's just gonna be praying and standing together." When I asked how Keketso and his partner coped, he attributed their ability to keep positive during the treatment process by "Just praving." It seemed that some couples found a sense of comfort in their spiritual beliefs, where prayer, religious reading, faith, and trust in their Being, assisted them to cope with the treatment processes they were engaging in, softening the treatment journey for couples a little.

Conclusion

Couples in my study portrayed their fertility treatment experiences as intricate, multilayered encounters which move beyond intrapersonal psychological experiences into relational, psychosocial domains. Here couples reflected on their experiences of their partner in treatment, and also extensively recognised their shared partnership experiences of fertility treatment within a larger social context. As such the findings of this study can be understood as portraying fertility treatment experience as a process rather than a single event which requires the couple to adjust. The findings of this chapter explored couples' fertility treatment encounters as dynamic, embodied psychosocial experiences, recognising the participants' social contexts as important aspects shaping their fertility treatment experiences and coping.

The following chapter is reserved for discussing these findings in relation to literature on fertility treatment experience, and looks closely at both how the research findings of my study contribute to the existing literature, as well as the novel contributions it makes in growing the body of existing knowledge.



PART E



<u>CHAPTER 7: DISCUSSION</u> Reflecting on Collective Sharing

You're giving me a million reasons to let you go You're giving me a million reasons to quit the show You're givin' me a million reasons... About a million reasons...

I bow down to pray I try to make the worst seem better Lord, show me the way To cut through all his worn-out leather I've got a hundred million reasons to walk away... I just need one good one to stay

Head stuck in a cycle, I look off and I stare It's like that I've stopped breathing, but completely aware 'Cause you're giving me a million reasons Give me a million reasons... About a million reasons

Every heartbreak makes it hard to keep the faith I just need one good one...

To stay ...

"Million Reasons"

(Ronson, Lindsey, & Germanotta, 2016, track 7).¹¹

¹¹ Discussion of the findings highlights the participants challenging fertility treatment experiences. The lyrics of this song talk to elements of those challenges



Introduction

I heard once that you are not the same at the end, as you were at the beginning of a PhD. While I can attest to that, I think the same could be said for any process, research or otherwise. To traverse a process by implication means that there is movement, and with that comes change. I could never have envisaged the spheres, or the trajectory of the insights I take away with me, personally, academically, and professionally. Experiencing the "human" elements of this process has been one of the most significant aspects to this research process for me. As I reflect on that some more, I recognise two main streams of development and learning here for me: The first is that this project amplified aspects of my professional responsibilities and secondly, created personal awareness which challenged some of the assumptions I held about myself, especially as it applied to my "researcher self".

With regards to my professional responsibilities, an aspect I recognised a long time ago was that as a psychologist, one of my responsibilities is to facilitate a therapeutic spacewhere I am invited into my clients' lives, not contexts that I hastily climb into. This aspect was solidified more so for me as I interviewed the couples in this study and throughout the process of working with their stories. I was reminded again of the privileged space I am invited into daily. The second stream of learning for me was the aspect of academic development. Undertaking this study not only provided me with the opportunity to formally research an area of interest, but also gave me the opportunity to explore my researcher self. When I began this process, I felt that it called for me to have my researcher self all figured out. After all, who undertakes a PhD and does not have this role fine-tuned? Admittedly, as it turns out, I did not and I later realised that I was probably not expected to either. This project taught me that the unfurling of the research process develops that part of the self. I wrestled with it at times as I tried to negotiate and develop different facets of what I felt was a new role. As I reflect on the personal elements of that process for me now, I realise that I have been a researcher all along, both from inside and outside a formal research space. My curiosity has shaped my researcher identity without me being overtly aware of it until now. It now has a formal name (i.e. researcher) as it pertains to this PhD context. This process has created personal and academic insight into a facet of my "Johari's window" so to speak, where what was once a blind spot, has become part of my arena that I now recognise (Luft & Ingham, 1961). I am a researcher daily! As it applies to my academic researcher self, I can continue to develop this facet further as time goes on.



My researcher self wrestled at times with my creative self, especially as it applied to the writing up of the thesis. There was a tug-of-war between how I perceived things "should" be written and between how I imagined it "could" be written. Against the backdrop of the formality that I associated with research and report writing, I at times felt like I had lost my way, lost my voice, and lost my style of writing. Perhaps it was not lost as much as challenged by my preconceived ideas of research, and while I cannot say that I have entirely overcome that now that I am concluding this journey, I can certainly say that I have grown a little more confident in embracing the creative aspects of myself in this process.

Upon reflecting on how I would approach the concluding chapter of my thesis, I considered many approaches and as I read countless PhD theses on an array of topics, my answer was nowhere to be found. I concede that yes, while all the documents I read had a discussion chapter, no concrete "how to" existed for my study. I kind of liked that because just like the results of this study reflected the nuances of participants' fertility treatment experiences, so too did the very same nuances serve as a reflective reminderto access and lean on my own. So, while I cannot say that the structure of this chapter falls entirely outside of what one may expect to find in a discussion chapter, and nor should it, I allowed my interpretations of both the existing literature and that of the participants' experiences to guide the flow of how I structured and sequenced the writing of their stories, rather than applying a structure to the telling of their experiences, so to speak.

My discussion on the participants' experiences begins with (i) how and why I did the research, and summarises (ii) what I did. I share (iii) what I found and how this answered the research question. I explore how the findings of this project makes a (iv) contribution to psychology, and what the implications of the findings have for both (v) practice and (vi) future research and in so doing, I identify the (vii) limitations of my research. I let the participants of this study close the discussion, as I provide the reader with their (viii) recommendations, coupled with my own. After all, it is a process we shared together.

How and Why I Did It

Home to my study, the REU, nestled within SBAH in Pretoria, South Africa was where my interest in understanding couples' subjective fertility treatment experiences wereformally embraced. I asked: "How do couples who have been diagnosed with primary infertility make sense of their experiences of fertility treatment within the South African public



health sector?" The REU provided the public healthcare context for sourcing the eight couples that I required for the study. With the assistance of the treating doctors, I reached eight couples who gave of their time to share their fertility treatment experiences with me. One might ask: "Why eight couples? Why not have more (or fewer) participants?" While there is no hard and fast rule when it comes to the number of participants in an IPA study, I was guided by Smith, Flowers, and Larkin (2009) who suggest the use of small sample sizes as the primary research concern is with providing a detailed account of individual experiences. The flip side of this, which I later arrived at, was that not all of the participants may continue their treatment process, and with that, would fall out of the research project.

I had a couple of ways that I could have handled my shrinking sample size. Firstly, I could have attempted to recruit additional participants to fill the spaces of those who no longer participated due to their treatment-related circumstances. The dilemma I faced with this option was twofold where I did not a) formally plan for this and, therefore, did not garner ethical approval for a "plan B" when submitting my proposal for ethical clearance, and b) I feel that picking up additional couples could have been the "easier road to travel" and one that did not reflect the outcomes of this study as they unfolded. In a sense, it felt as if I would be engineering the circumstances to ascertain answers to my research question, when in fact the fallout of participants was providing me with some of the answers. In this sense, four of the eight couples discontinuing treatment due to affordability was in itself a finding. So, I took the risk to continue with the project as it was naturally unfolding and in so doing, telling these participants' stories of financial and emotional difficulty in line with the developments of the project. My overt experiences of participants falling out of the project were initially unsettling but at the same time shifted my outlook again on how research "should" be done, and helped me focus on what "could" be done. I chose to keep each of the participants' stories alive in this thesis in keeping with this lesson and because I felt that their contributions were no less valuable, even if their treatment time was short-lived and their stories ended prematurely. It was my hope going in to this that by researching couples' subjective experiences of fertility treatment, the findings of this study would not only broaden healthcare professionals' knowledge on the topic, but could be applied professionally in the work they (and myself included) engaged in with couples during treatment. Couples discontinuing treatment due to financial and emotional challenges is a node that, as healthcare professionals, we can draw on as we design treatment plans that may require more short-term interventions in the developing world context. Although I speak



more about this in the recommendations section later, this point, however, does link with the primary and secondary goals I wanted to achieve in undertaking this project.

The primary goal was to attempt to (i) understand couples' joint fertility treatment experiences. The secondary goals of this project that would assist in actualising the former goal were to (ii) provide an opportunity for couples to share their experiences, where they could (iii) make sense of their fertility treatment experiences, the results of which would be utilised to (iv) establish guidelines for healthcare professionals working in this context. I now share with the reader what I found and how this answered the research question and, therefore, achieved the goals I had set out to.

What I Found and How It Mattered: Answering the Research Question

I feel a few side notes may be helpful to the reader before I plunge into a summary of the findings, as they may assist in positioning the findings. The first aspect of the findings that I would like to mention, which informed the way I chose to report on the data, pertains to the volume of data that was generated from the interviews. Despite participants discontinuing treatment at different phases of the research process, rich experiential data was generated which required careful analysis and thoughtful reporting. So, although my time with half of the participants was limited, they nevertheless provided rich descriptions on their treatment experiences. Furthermore, the reader will notice that I chose to present the findings in two separate chapters. This was motivated by a) attempting to report on the data in an accessible manner, and b) mirrored how I was attending to facets of the research question in delineating couples' joint fertility treatment experiences. To be clearer, I attended to the context of treatment (public healthcare sector) experiences in the first of the two findings chapters (Chapter 5), followed by the interpersonal and social contextual aspects of their treatment experiences (Chapter 6), both of which highlighted significant aspects that shaped the participants' experiences of fertility treatment. This concluding chapter then (Chapter 7), can be viewed as integrating the findings, and thereby synchronising the results in order to answer the research question more cohesively.

Participants drew on their experiences of private and public healthcare fertility treatment as well as their interpersonal, social, and spiritual contextual experiences making sense of their fertility treatment experiences in the public health sector. Transcending the physical



experiences of the services they encountered at the REU, couples portrayed their fertility treatment experiences as being punctuated and shaped by their experiences of their partner in treatment and also extensively recognised their shared partnership experiences of fertility treatment within a larger social context. As such, I understand the findings of this study as portrayingfertility treatment experiences as a process rather than a single event (or series of events), which necessitated adjustment (Stanton &Dunkel-Schetter, 1991b). Taken together, the findingsshare couples' fertility treatment encounters as dynamic relational experiences, recognising the biological, coupleship, and social contexts as important aspects in shaping their fertility treatment experiences.

I discuss these findings more comprehensively below by first discussing the aspects of the findings that were (i) congruent with the literature, followed by those that stand out as (ii) surprising in relation to established literature and, therefore, make an original contribution to the field of Psychology. The master themes direct the discussion of findings as they relate to the literature as well as the discussion on the surprising nuances of this study. The words in bold are intended to draw the reader's attention to the narratives (superordinate themes) that highlighted how the participants of this study made sense of their fertility treatment experiences.

Findings that were Congruent with ExistingLiterature

Upon considering the findings of my study against the backdrop of existing literature, I recognised pockets of the results which were congruent with literature in the field of fertility treatment experiences. I commence the discussion of the findings by addressing the contexts that shaped couples' fertility treatment experiences, before moving on to the findings that pertained to their experiences of their partner, their partnership, and social contexts they identified as shaping their fertility treatment experiences.Collectively my research findings support the literature on involuntary childlessness as being a multidimensional health issue, which can significantly impact the individual, the couple system, as well as havingthe potential to reverberate into multiple contexts (Daly & Bewley, 2013; Saridi & Georgiadi, 2010). On that note, I look at the contexts that shaped the participants' experiences of fertility treatment in my study.

Contexts shaping the participants experiences of fertility treatment. There were specific aspects of the participants' private and public healthcare experiences which supportedmy review of the literature. In particular, the findings of this study that were



congruent with current literature related to affordability and, by implication, accessibility of fertility treatment in the South African context. I look at the findings of the private healthcare context before proceeding with the literary contributions that my study makes in respect of the public healthcare sector.

Private healthcare experiences which support the literature. Couples who participated in my study expressed experiencing **private healthcare** as an **unaffordable** option due to **medical aid limitations** and the **absence of personal accounts**. In the end, the absences of both lead to private fertility treatment being a dead-end option for participants. The developing world literature highlights the aspect of **affordability** as a barrier not only in terms of service delivery, but also in accessibility to services offered to patients (Huyser & Boyd, 2012; Ombelet, Cooke, Dyer, Serour, & Devroey, 2008). Although the aspect of **affordability** aligns with Sharma, Mittal, and Aggarwal's (2009) call for more affordable fertility treatment options in developing countries, it is a general plea for reducing treatment costs, both to the service provider themselves and for the patients who would hope to utilise the services in the first place (i.e. private healthcare or public healthcare fertility treatment). For those not utilising private healthcare fertility treatments, their experiences of fertility treatment in the public healthcare context were layered.

Public healthcare experiences which support literature. Participants shared that prior to engaging in fertility treatment at the REU, they had **preconceived perceptions** about the quality of fertility treatment in the public healthcare context. This is congruent with developing world literature which describes fertility treatment in resource-poor communities as being overwhelmed by healthcare systems that are challenged by financial constraints, limited budgets, and infrastructure issues (Robert & Nachtigall, 2006; Sharma, 2009). However, the participants' engagement with fertility treatment at the REU challenged and created a shift in their perception of public healthcare treatment as they expressed experiencing not only multiple public healthcare services, but were satisfied with the services for the most part (addressed under "surprising findings", page246).

Four of the eight couples who terminated their fertility treatment, cited **affordability** as the barrier to continuing treatment. These findings support the claims that accessibility to and engagement in ART is expensive, and only accessible to the privileged few who can afford the financial costs (Huyser & Boyd, 2012; Huyser & Boyd, 2013; Huyser & Fourie, 2010;



Ombeletet al., 2008; Theoh & Maheshwari, 2014). While I am not claiming that the fallout rate for my study can be generalised to the South African population, this finding however, is supported by the existing literature on the issue of affordability, highlighting Ombelet et al.'s (2008) call for the provision of more affordable ART options in developing countries.

Participants shared that their fertility treatment experiences were shaped by **informative services** offered by the unit. Through being informed, it not only created **participant understanding**, but also **treatment-related certainty**. Through being informed, couples expressed understanding both **anatomical** and **procedural** aspects of their treatment, which created **participantcertainty** and a sense of **empathicunderstanding** when the healthcare staff attended to the emotional aspects of treatment. This supports the notion that the scope of the health professionals working in the field of infertility can be vast, including but not limited to providing support, treatment, and education (Boivin & Kentenich, 2002; Covington, 1995). While some couples experienced being adequately informed, others felt that more could be done in providing information to patients. Participants experienced consultations as **confusing** at times, especially when medical terminology was used during their interactions. These findings confirm that healthcare workers should be mindful of the level of education of their patients, so that information delivery is given in a manner that is understood so that clinic attendance is not discouraged (Dyer et al., 2002; Ndowa, Lusti-Narasimhan, & Unemo, 2012; Van der Spuy, 2009).

Aside from the context-specific findings as it pertained to public healthcare treatment, participants shared their coupleship experiences of public healthcare fertility treatment which aligned with existing literature.

Couples' shared fertility treatment experiences. Involuntary childlessness and with that the impact and resultant implications, can have far-reaching consequences with cultural, individual, economic, and social contexts being affected (Hammarberg & Kirkman, 2013; Ombelet & Campo, 2007). My research findings confirm that infertility permeates not only the couple system, but also social contexts outside their partnership. I begin the discussion of my findings by addressing participants' reflections of their partner in treatment, before moving to their shared experiences of treatment which support current literature.



Experiencing my partner: Findings which support the literature. Male participants in my study expressed concern for their **partner's wellbeing**, and with that, the wellbeing of their relationship. Here, men felt a sense of loss of control and worried about their partner during treatment (Hjelmstedt, et al., 1999). Consistent with the literature, their **concern** centred on their partner's health and was accompanied by feelings of **helplessness** in the face of their partner's emotional and physical pain experiences. In recognising the difficulty their partners were experiencing, some participants expressed feeling **insecure** in the couple relationship as men contemplated the possibility that their partners may consider ending their relationship to make it easier for their partner to attain parenthood. Whilst men were concerned about their partner during their fertility treatment, their experiences were not absent of **frustration**. Men placed importance on their partner following their treating doctor's recommendations and experienced behaviour outside of those guidelines as signalling noncompliance, resulting in frustration and increased conflict (Wirtberg, Moller, Hogström, Tronstad, & Lalos, 2007). Female participants' experiences were slightly different from their partners, although there was one commonality.

Female participants, on the other hand, placed importance on receiving **support** from their partner during the treatment process (Beutal et al., 1999), while at the same time recognising that their partner, too, may require **support**. Fisher and Hammarberg(2012) recommend that continued research may inform psychologically informed support. In this vein, when considering the aspect of male support, research points to men experiencing infertility, and with that, fertility treatment as a stressful process, further highlighting that men, too, may require support (Peronace, Boivin,& Schmidt, 2007).Although women expressed feeling supported by their partner, some women, like men in this study, identified feeling a sense of **insecurity** developing within the couple relationship as they explored the possibility that their partner may choose to end their relationship to attain parenthood more easily. Fertility treatment experiences thereof can threaten the stability ofmarriages (Sundby, 1997; Wirtberg, Moller, Hogström, Tronstad, & Lalos, 2007).

Aside from participants' reflections and experiences of their in-treatment partners, there were joint fertility treatment experiences which supported existing literature.

Coupleship experiences of fertility treatment which support the literature. Participants in my study shared experiencing public healthcare fertility treatment as a **challenging**



endeavour. The research findings communicate that other thanaffordability, couples shared that their fertility treatment experiencescan be understood as an all-consuming process, intruding on couples' experiences of their daily lives (Redshaw, Hockley, & Davidson, 2007). These research findings support the main thrust of the psychological consequences theories which take a broad view of involuntary childlessness and fertility treatment experiences. Proponents of these theories view fertility treatment experiences as representing an allencompassing and emotionally difficult process for individuals and couples (Greil, 1997; Enveloping couples'routines, thoughts, time, and money, couples Menning, 1980). experienced fertility treatment as a challenging process all-round (Daniluk, 2001). Female participants in particular addressed the physical intrusiveness of treatment and the disruption treatment brought to their daily lives. This echoes Beutal et al.'s (1999) findings on fertility treatment experiences of women who described treatment as having a greater impact on their daily lives and, therefore, required more support, whilst husbands, on the other hand, felt a sense of responsibility for the couples' infertility. Expanding on the all-consuming aspect of treatment, couples identified experiencing **repetitive thoughts**, which frequently drew them back to their fertility treatment experiences. When it came to couples' experiences of time challenges, couples expressed a dichotomy between treatment disrupting work and conversely, work disrupting treatment at times. In further making sense of their fertility treatment experiences, there was no escaping the challenges of the **financial costs** of treatment (Huyser & Boyd, 2012; Huyser & Boyd, 2013; Huyser & Fourie, 2010; Ombelet et al., 2008; Theoh & Maheshwari, 2014). Couples were required to plan their finances accordingly, which meant for some couples that they were faced with postponing personal short-term goals, or were prepared to face financial ruin in the quest to have a child. Although treatment in the public health sector is less expensive than privately offered treatment, couples in my study that were undergoing public-based treatment were faced with wanting a child at a cost, which for most, was not easily negotiated and required that they plan their finances or discontinued treatment (Huyser & Fourie, 2010; Theoh & Maheshwari, 2014). Another challenging aspect of couples' fertility treatment experiences were their experiences of the treated body as a problematic adjunct to the couple relationship.

Participants expressed that they experienced the **treated body** as presenting a **reproductive hurdle**, where, in its treatment, it obtained a **problematic illness identity**, both within and outside of the context of the couple relationship (Greil, Slauson-Blevins, & McQuillan, 2010). In an attempt to garner control in the treatment process, the administration



of **medication**served an important function, albeit that medication held a precarious position in the treatment process. With the emergence of ART, particular emphasis has been placed on the female partner being identified as the patient needing treatment, regardless of the cause of the infertility (Covington & Burns, 2006; Marsh & Ronner, 1996). In relation to the treated body, men in my study reported feeling like a **bystander** in treatment, which was not only perpetuated by the **medical attention** given to the treated body of their partner, but also through **communication** practices during consultations (Agostini et al., 2011; Schmidt, 2009). These findings support that infertility, as an area of interest, has maintained a dominant medical narrative in which patients have been women and the focus of treatment has primarily been on the reproductive system (Marsh & Ronner, 1996). My research findings concur with Dyer et al.'s (2004) call for effective integration of men in infertility management and for providing the option for men to access counselling and education.

Although couples expressed experiencing fertility treatment as an **emotionally challenging endeavour** shaped by **emotional lows**, couples also shared experiencing treatment-related **highs** albeit during an emotionally challenging process. The emotional lows were marked by **pain** and **difficulty**, **anxiety**, and **stress**, as well as **sorrow** and **disappointment** (Fisher &Hammarberg, 2012). The emotional highs of treatment were shaped by feelings of **hope** related to possible treatment success (Blenner, 1990). These research findings are congruent with **stress and coping theories** which understand infertility and its treatment as a stressor, where fertility treatment, emotional distress, and events accumulate over time, requiring activation and utilisation of coping strategies to allow adjustment and to ensure emotional and marital equilibrium (Stanton & Dunkel-Schetter, 1991b; Taymor & Bresnick, 1979).

The aspect of couples' survival experiences which were shaped by their joint resourcefulness, is what I attend to next. Couples in my study who shared their experiences of fertility treatment as a **coping opportunity**, shared several**coping strategies** that helped them get through trying times during their treatment process. Participants attended to the role of **communication** in helping them cope. For some participants, openly communicating their experiences helped them cope, while for others avoidance of communication was more useful. For some of the participants, infertility created a sense of closeness within their relationship (Greil, 1991; 1997) and by talking about their experiences, men feltthat infertility was a shared experience which, in turn, seemed to strengthen their relationship (Webb & Daniluk, 1999).



Couples' focus on **conflict resolution** became a coping tool for some, where they learnt the value in resolving conflict differently. Participants highlighted **stress management** strategies that they developed as methods for neutralising treatment-related tension and others referred to an awareness of their **treatment outlook**, where they made a conscious effort to remain positive and embrace the outcomes and possible disappointment that may be an inevitable part of treatment. When examining the literature on distress and coping strategies among infertile individuals, it seems that my findings align with the benefits that recognise the need to mobilise coping strategies during fertility treatment. In particular, research shows that stress is lessened considerably when individuals have access to and utilise social coping resources, are in growth-fostering relationships, have the support of their partner, and have family support (Gibson & Meyers, 2002). Together with couples identifying the development of coping strategies to manage their stressful treatment experiences, participants also identified the social context as shaping their fertility treatment experiences fails to recognise (Greil, 1997; Stanton & Dunkel-Schetter, 1991a).

I close the discussion on my findings which support existing literature by exploring the social contexts that shaped participants' joint fertility treatment experiences, and how these systems facilitated (or in some instances, hindered) coping for couples during their treatment process.

Social contexts shaping couples' fertility treatment experiences which support the literature. For the people who struggle with involuntary childlessness, they confront a multi-layered set of biological, psychological, social, and spiritual experiences (Roudsari & Allan, 2011). My research findings support this view, in that fertility treatment experiences for the participants in this study were not confined to the borders of their coupleship but were also shaped by various social contexts. Couples' shared experiences that drew them closer to, or propelled them further away from their family, friendship, work, community, and spirituality. Aspects of each context not only shaped participants' joint fertility treatment experiences, but also played a role in assisting or, conversely, hindering couples coping with their fertility treatment. These findings support the psychosocial context approachwhich providesa multifaceted understanding of the factors which can influence infertility and treatment experiences. Here infertility is not solely viewed as an individual psychological experience, but is experienced socially as well, occurring within the context of the couple's



social milieu and, as such, is better understood as a "process" rather than an "event" (Greil, 1997).

For the couples in this study, fertility treatment permeated beyond the borders of the couple relationship, becoming a systemic issue. Couples' experiences of their family context during fertility treatment were shaped by their family expectations to grow the family unit and in some instances aligned with birth order expectations to produce offspring sooner rather than later. In this regard, my findings support the view that infertility can be experienced and viewed as a crisis in family developmental genealogy, impeding the family's ability to grow (Daly, 1999). For some couples who did disclose their fertility treatment to their family, the act of sharing information increased their experiences of connectedness during treatment while others expressed experiencing judgment regarding their childlessness. Prejudicial experiences extended beyond the confines of gender, where both men and women in this study shared their encounters with me. In Africa, women are frequently stigmatised, ostracised, isolated, and neglected by their family and their community for failure to achieve pregnancy (Hammarberg & Kirkman, 2013). As a way of limiting discrimination and judgement, some couples reported that they chose to keep their infertility and their treatment as a private matter. This is in line with family system theories which describe rigid boundaries as developing in response to infertility in an attempt to secure the treated couple's privacy, which has the potential to lead to isolation from family (Burns, 1987). Infertility is considered taboo in many communities, especially pronounced in Africa where growing the family unit is praised and revered (Hlatshwayo, 2004), and therefore, is not a subject that is easily talked about, even under research conditions.

Although the majority of the participants of my study chose to keep their treatment private, for those couples who shared their active involvement in fertility treatment with their families, some shared that their family played an important role in their **coping** and shared viewing it as a positive experience. Family seemed to assist couples in **coping** through **normalising** their treatment process, through mutual sharing. Family also illustrated their **support** by praying for the couple, messaging words of support, as well as through displaying **curiosity** regarding their treatment. When examining the literature on distress and coping strategies among infertile individuals, stress is lessened when they receive support, one of which is family support (Gibson & Meyers, 2002).



When it came to the **friendship context**, participants expressed dichotomous friendship experiences. Couples expressed feeling that their friends **lacked understanding** of their fertility difficulties and treatment-seeking experiences. When participants felt a sense of emotional disconnect due to a lack of perceived understanding, some participants then assumed an **avoidant communication style**, where they made a conscious effort to not talk about fertility treatment with their friends. On the other hand, some participants experienced the surprising development of **new friendships** within the REU. Here, couples expressed feeling a sense of **mutual understanding** and **connectedness** through shared fertility treatment experiences with fellow patients. Although participants who chose to disclose their treatment experiences with their friends did not always feel fully understood, some couples did experience support from their friends which was helpful to them in their **coping** with treatment.For both men and women in my study, friendships as they occurred either in person or online, provided participants with much-needed **support**, which was shaped by their experience of **connectedness** through mutual understanding and a sense of shared treatment experience.

Couples expressed experiencing their **workcontext** as shaping their fertility treatment experiences in a number of ways. During their fertility treatment, work became a place for measuring their **developmental success**through making social comparisons with colleagues. Couples' experienced a **clash** between work- and treatment-related commitments, where a **triad** developed requiring couples to prioritise between work, treatment, and relationship responsibilities, as the juggling of all three was not always easily attained. A participant sharedthat work became a context for ridicule, **judgement**, and assumptions, which were experienced as painful aspects to her fertility treatment investigation. Judgemental worktreatment-related experiences negatively shaped her initial fertility investigations, which informed the participant's treatment-related **privacy**. Although not all participants chose to keep their fertility treatment private, one couple experienced their work environment as facilitating **coping**through **accommodating** treatment-related time off.

Couples shared arduous **community context** experiences during their fertility treatment as it too, like the family context, placed **expectations** on couples to grow the family unit. Herein lay the difficulty as couples faced involuntary childlessness against the backdrop of pronatalistic societal expectations.Participants' experiences in my study aligned with the dilemma that involuntary childlessness poses since African countries like SA are generally pronatalistic, with many cultures placing great importance on expanding the family unit



(Barden-O'Fallon, 2005; Feldman-Savelsberg, 2002; Hollos, 2003; Parry, 2005; Pashigian, 2002; Pearce, 1999; Remennick, 2010; Sundby, 2002; Sundby & Jacobus, 2001; Van der Spuy, 2009). In some instances, the expectation to grow the family lead to community members questioning the couple about why that expectation had not been met within a certain time frame. In this regard, couples expressed experiencing their community as probing and judgmental as it related to their involuntary childlessness (Dever et al., 2008; Ombelet & Campo, 2007; Ombelet et al., 2008). Women in my study were implicated as being the cause of the couple's infertility. In these instances, women were viewed as ultimately responsible for the problem and were, therefore, required to take responsibility for the solution. This highlights the socially appointed burden that women have unduly assumed for couples' childlessness (Covington & Burns, 2006). Men, on the other hand, experienced feeling a sense of accountability and responsibility for directing the couple regarding treatment. Men did not escape community discrimination, where they encountered name calling, gossiping, and were faced with numerous questions regarding the couples' childlessness. My research findings support stigma theories which understand experiences of stigma across both gender-specific infertility and infertility-specific individual distress within cultural contexts (Covington & Burns, 2006; Goffman, 1963; Sandelowski & de Lacey, 2002). When it came to the aspect of coping, none of the participants in this study shared the role of the community in facilitating coping during treatment. This could have been for a number of reasons; one of which may be how community expectations and judgemental experiences may have shaped couples' resistance to access community support (Whiteford & Gonzalez, 1995). On the other hand, the absence of community support coming up in my research may also reflect an area that I may have failed to attend to during the interview process. Couples, as members of their pronatalistic communities are faced with enduring fertility treatment against the backdrop of stigma, prejudice, blame, and feeling a sense that they are developmentally stunted (Matthews & Matthews, 1986, Miall, 1985; Ombelet & Campo, 2007). It is no wonder then, in the absence of community support, that many chose to access or conversely, disconnect from their spiritual beliefs.

Participants shared experiencing dominant religious**expectations** to grow the family unit, synonymous with family and community context expectations, and for some couples, religious doctrine was experienced as **disapproving** of fertility treatment seeking (Roudsari, Allan, & Smith, 2007; Schlumpf, 2016; Sewpaul, 1999). Couples' spiritual experiences during fertility treatment were not only punctuated by spiritual dilemma, where for some participants, they felt



a sense of deepened spiritual **connectedness** through increased prayer and through their reading of religious material. Although some participants' spiritual experiences were shaped by their experiences of disapproval and for others a sense of connectedness, some couples reported experiencing spirituality as facilitating their **coping**. Spiritual **support** was accessed and came in varying forms. Some couples found strength and hope through prayer and increased scripture readings, while others looked for and made sense of external signs in their environment as spiritual signs from their Being, giving them a sense of hope that all would turn out alright.

Although the findings of my study contributed to the current literature, I was also surprised by several the findings.

Surprising Findings

Fisher and Hammarberg's (2012) review of the literature identified pervasive gaps in knowledge about factors governing treatment seeking, continuing with treatment, and deciding to terminate treatment. Research has focused less on infertility experience for individuals and couples, and more on the psychosocial responses to treatment (Inhorn, 2002; Van Balen & Inhorn, 2002). My study begins to isolate some of those factors that shape couples' fertility treatment experiences in the developing world context. Couples in my study shared a number of unanticipated contextual (private and public healthcare context) fertility treatment experiences, as well as relational (social contextual) experiences that I had not come across in the literature that I had surveyed. I begin with a discussion of the findings which provide unique insights into the contexts that shaped participants' fertility treatment experiences, followed by a discussion of the unique elements of the social contexts that shaped their joint fertility treatment experiences.

Contexts shaping the participants' experiences of fertility treatment. When it came to the contextual findings, there were a few aspects of the participants' experiences that I encountered as surprising in light of the existing literature on fertility treatment experiences. The first was couples' private healthcare experiences in respect of unsatisfactory service delivery experiences, which seemed to pale in comparison to their public healthcare experiences. Aside from issues regarding affordability discussed in the preceding section, couples cited **disappointment** in their experiences of services received in the private sector. Public healthcare experiences, in contrast, were experienced as providing an array of services, which for the most part, participants were happy with. The irony of this is surprising as I would



assume that the more expensive services would naturally be "better" (in type and quality). But this was not the experiences of the couples in my study.

Surprising private healthcare experiences. While my study focused on public sector fertility treatment experiences, three couples explored their private sector experiences. These experiences not only provided insights into their experiences of **private healthcare** fertility treatment which helped me understand their public fertility treatment experiences better, but also provided a rationale for opting for public healthcare treatment later.

For those who tried private healthcare treatment initially, aspects other than finances also shaped their fertility treatment experiences. In addition to the high costs of treatment representing an obstacle to accessing or continuing private healthcare treatment, participants also shared that their private fertility treatment experiences were stippled with disappointment. Participants' disappointment in private healthcare fertility treatment was shaped by their experiences of **poor patient care** as it related to both **feedback** and **value for money** experiences, both of which were cited as disappointing. For the couple who accessed spermbank-only treatment as a more affordable private fertility option, their experience of disappointment was shaped by the limited nature of services offered and whether such a service should be offered to the public in the first place, in the absence of a detailed fertility investigation. Their critique of a sperm-bank-only option highlights the breadth of contextually meaningful experiences of couples undergoing fertility treatment and the evaluative aspect of those experiences. This was surprising because I thought that perhaps their disappointment may have rested on the cost component of private fertility treatment and the barrier this may have represented in continuing private treatment, where in fact their concerns centred on the value of the interactions in respect of the costs of treatment, the scope, and evaluating the ethical aspects of providing the services in the first place when it came to certain private healthcare fertility treatment services. Although Huyser and Boyd (2012) provide a comprehensive cost comparison between private healthcare versus public healthcare treatment costs, their focus did not venture outside monetary boundaries into other facets which can shape couples' experiences of private sector treatment. Thus, the findings of this research project could be seen as surprising as they share couples' experiences of private healthcare fertility treatment as disappointing regarding patient care and limitedfeedback and in some instances, limited in scope, which called into question the ethical nature of offering these services.



Surprising public healthcare experiences. Contrary to private healthcare experiences, participants who were actively accessing fertility treatment at the REU at SBAH, shared that they encountered a breadth of fertility treatment services at the REU. Couples' fertility treatment experiences were shaped by comprehensive, conversational, informative, and facilitative service experiences. These findings were in direct contrast to the disappointing experiences of those participants who had accessed private fertility healthcare, even if their treatment there was brief or limited in scope. I have not come across these or similar experiences in the developing world literature that I surveyed. What I did hear is that they experienced more positive encounters than they did negative, and that is surprising in light of previous literature which depicts public funded fertility treatment as having its own set of challenges which ultimately impacts service affordability, accessibility, and delivery (Huyser & Fourie, 2010; Teoh & Maheshwari, 2014). The conditions of the country impact not only its people, but also public and tertiary ART units, as well as private practices insofar as their ability to adequately provide reproductive health screening and fertility treatment possibilities (Huyser & Boyd, 2013). However, the findings of my research, not only confirm that affordability can have a profound impact on patients' ability to sustain treatment, but it also illustrated a surprising element to public healthcare experiences in that couples shared experiencing a varied set of services, which they expressed as being satisfied with overall. This is a triumphant finding that in a developing country one could find a public-sector fertility treatment unit that provides an array of comprehensive treatment services to the public. Although it can be said that Robert and Nachtigall (2006) and Sharma's (2009) assertion that couples attempting to access fertility treatment in resource-constrained communities are often faced with healthcare systems that are challenged by financial constraints and limited budgets, the infrastructure issues raised were not aspects that couples in this study emphasised as particularly significant to their fertility treatment experiences.

When it came to participants' **comprehensive service experiences**, couples shared that these were shaped by the staff's **professional conduct** as it related to their detailed investigations and explanations and their willingness to **engage consultant opinions** when necessary. Patients' experiences of comprehensive public-sector services are not something I have come across in the literature. Another finding from my study that I found surprising, was that participants did not only express their satisfaction with the comprehensive medical treatment they experienced at the REU, but for some participants, their treatment experiences were also shaped by **conversational service experiences**. Couples shared that they were



provided a time and place to talk about their fertility treatment experiences during consultations and could, therefore, emotionally check in on their fertility treatment experiences. I interpreted this in a number of ways; one being that an appointment time did not only signal a physical fertility check-up or procedure, but also signalled an appointment with each other to talk about their fertility treatment. In this instance, consultations held physical and emotional significance for participants in this study.

In addition, participants shared that their fertility treatment experiences were shaped by **informative services** offered by the unit. Through being informed, it not only created **participant understanding** regarding the different elements of their fertility treatment, it also **created treatment-related certainty**. While some couples experienced being adequately informed, others felt that more could be done in providing information to patients. Although the literature attends to the importance of and need for information sharing during fertility treatment, I have not come across literature which expresses that couples accessing public healthcare fertility treatment receive satisfactory informative services. Instead, developing country literature focuses on the struggles of the system and how this translates into patient care (Ombelet et al., 2008; 2014; Robert & Nachtigall, 2006; Sharma, 2009; Theoh & Maheshwari, 2014). It does not tell the less dominant story of how units like the REU experience difficulties, but somehow manage to get it right to provide fertility treatment and services that patients are satisfied with. Another triumph!

The intricacies of the aspects that shaped participants'**facilitative service experiences** were surprising to me. The couple-doctor relationship as a facilitative facet of fertility treatment was valued highly by the participants of my study. It was there that **rapport** was established through **empathic interactions** during their experiences of **personalised consultations** with their treating doctors. Couples experienced consultations as creating treatment-related **opportunities**, although, they experienced **unintended paradoxical interactions** with their treating doctor at times. This highlighted the importance of **communication** for participants. Although this confirms Burns and Covington's (2000) view that there has been a "medicalisation of infertility" which misleads people into seeking medical treatment, and where people take upa "passive patient role" in the patient-doctor relationship, their view is a rather critical and bleak one at that. While this research does confirm that the medicalisation of infertility can be associated with medical jargon and terminology, which may obstruct patients' understanding of their treatment process (Ulrich & Weatherall, 2000), their research does not



actively recognise the interpersonal importance of the doctor-couple relationship as being a potentially positive adjunct to couples' fertility treatment experiences. My research, however, recognises that couples placed significance on having one treating doctor manage their fertility treatment process, and highlighted the value of empathic and personalised consultations as positive treatment experiences at the REU.

Whilst I cannot claim that the participants in this study only had positive fertility treatment experiences, for the most part when it came to the context in which treatment was received, their public-sector experiences were, on the whole, positive ones in the midst of a challenging infertility process. A natural progression from here would be to discuss the aspects of my research findings that contribute to the field of psychology. This discussion follows.

The Contribution to Psychology

Whilst Covington and Burns (2006) share an optimistic view of the development of social science research in the field of involuntary childlessness, they do identify remaining gaps in the literature. The salient concerns raised have been that research has primarily centered on the experiences of white, educated, heterosexual women residing in developed countries. There have been less contributions focusing on experience of culturally diverse men and women from resource-constrained communities, who reside in developing countries with limited access to treatment (Greil, 1997). Although Dyer et al. (2008) conducted a study of couples living in a developing country and who were receiving fertility treatment, their focus was on men and women's desire for children, and found that their parenthood motives were shaped by pronatalistic values held in the community; therefore, having social implications for couples. Surprising then that in communities that place significant value on having children, little focus has been placed on the provision of mental health services in the developing world and, therefore, leads to inconsistent standards in the provision and utilisation of psychotherapeutic support services as an adjunct to infertility treatment. Against the backdrop of the gaps highlighted, I explore the contributions I believe my research makes to the field of psychology as it pertains to (i) contributing to the body of literature on fertility treatment experiences and (ii) methodological contributions in SA.

Contributions to the Body of Literature

My research projecthighlighted the need to address the aforementioned critique by providing psychological insights into South African couples' experiences of fertility treatment



in a public health fertility clinic. Couples utilising the REU primarily come from resourceconstrained communities, are from various cultural and educational backgrounds, and have divergent infertility histories which have lead to their referral to the clinic. I believe this project illuminated various aspects that shape couples' fertility treatment experiences in the public health sector, not only demonstrating that it is important for couples to be able to access support, but to provide support which is informed and appropriate. When considering whether counselling services are necessary, one only needs to look at the research findings that talk to their lack of community support and the level of privacy that participants maintained in this study. Making support services available and accessible to patients in treatment centres may increase patients' use of them.

In particular, I believe my research findings make an additional contribution to psychology by providing insights into couples' contextual experiences of treatment in both the private and public healthcare contexts in SA. Although I cannot say that these insights reflect the majority of the REU patient experiences, I can say that the findings highlight aspects to fertility treatment experience that I have not come across in the literature as it pertains to service delivery experiences. Disappointing private healthcare fertility treatment experiences that extended beyond the aspect of affordability into the realm of patient care, and the lack of extensive feedback for the price they were paying for treatment, is surprising in light of the value for money services they expressed experiencing at the REU, albeit that there were affordability issues there too. Couples' public healthcare treatment experiences in my study were shaped by (i) comprehensive, (ii) conversational, (iii) informative, and (iv) facilitative service experiences, and as such contrast the dominant narrative that developing world fertility services are below standard.

Although additional aspects of my research findings contribute to the existing literature with regards to participants' interpersonal experiences (i.e. reflections on their partner and joint partnership fertility treatment experiences), my research delves into the intricacies of these aspects that shaped couples' fertility treatment experiences, further recognising social contexts such as family, friends, work, community, and spirituality as important facets which shaped couples' fertility treatment experiences. In this sense, couples' public-sector fertility treatment experiences are not only shaped by the context in which treatment and services are received, but are also shaped by their partnership and social contexts. These contexts should be considered when healthcare professionals are developing psychological interventions.



I believe the intricacies of experiences that I was able to access and share here, were made possible, in part, because of the methodology utilised in this study (i.e. IPA).

Methodological Contribution

In my examination of the SA literature, no research on infertility or fertility treatment experiences have been initiated in SAfrom an IPA perspective. In comparison, there are many international studies which have been conducted and that focused on couples' fertility treatment experiences utilising an IPAmethodology.Most of these studies were conducted in developed European countries and conveyed the experiences of couples living in developed countries(Phillips, Elander & Montague, 2014; Provoost et al., 2009).My project will therefore be the first one that was conducted in SAthat has researched couples' fertility treatment experiences utilising an IPA methodology.

What then are the implications of my research findings? I address the answer to this question next through specifically focusing on guidelines healthcare professionals could utilise when developing supportive interventions for couples undergoing fertility treatment. These guidelines are based on the findings that I have discussed in both the findings sections of the thesis, as well as those found in a condensed format here in the discussion chapter. These guidelines should not be viewed as a set of criteria or list to get through when working with couples; rather, as a guideline only. My belief is that the couples that we work with teach us the domains in which they require support; we simply need to listen closely for them. In so doing, we can design interventions that are informed, and ones that recognise the unique circumstances of the couples we work with, while simultaneously developing our professional skills as we tailor our therapeutic approach. These guidelines represent participants' interpretations of their experiences, together with my interpretations of their interpretations.

The Implications for Practice

Dyer et al. (2005) state that effective interventions will be those that implement a biopsycho-social strategy; my research confirms a holistic approach to provision of support. Through being informed about the psychosocial aspects of fertility treatment experiences of couples, healthcare professionals' knowledge of clinical issues is increased, informing the provision of meaningful therapeutic support (Greil, 1997). Based on the findings of my study that highlight participants' experiences as mediated by numerous contextual and interpersonal factors, the development of holistic patient care is called for. In this regard, I suggest an



integrative approach to patient care that recognises and works with the bio-psycho-socialspiritual aspects of fertility treatment experience.

Other than fertility treatment seeking indicating that they require medical intervention, my research indicates that patients may require a time and place to emotionally decompress. In this regard, counselling may be indicated. What happens then to couples who do not have these services readily available? Many keep quiet, attempting to deal with it on their own or as a couple. In this regard, where possible, fertility treatment centres may want to consider expanding their **facilitative services** to incorporate counselling services. Although many private healthcare centres may provide this service (at a cost to the public), I do not think this is always provided in the public healthcare centres in extending their already very tight budgets to now incorporate counselling fees as well. In this regard, a possible way to manage that could be to utilise training psychologists and offer a practicum where this can both enable the provision of counselling services to the public, and at the same time assist in developing student psychologists' counselling skills. Below are a number of guidelines that healthcare professionals can use to guide their process with couple interventions:

Development of Short-term Supportive Interventions

Couples discontinuing treatment due to financial and emotional challenges is a node that as healthcare professionals we can draw on as we design therapeutic interventions that may require more short-term patient care in a developing world context. I provide guidelines below which highlight some of the aspects that practitioners can consider when designing supportive interventions for patients who are undergoing fertility treatment:

Integrated approach to counselling and support. When developing short-term interventions, practitioners could consider the bio-psycho-social-spiritual facets to fertility treatment experiences for couples. Development of supportive interventions then should be viewed as focused, yet comprehensive treatment which integrates both treatment context experiences, as well as social contextual experiences.

Treatment is a coupleship experience: Recognise men as equal partners. Healthcare professionals should be mindful of the inclusion of men in the treatment process, as they, too, experience a number of emotions as a result of their treatment experiences.



Utilise easily understood language when working with couples. It is important for couples to fully understand their treatment process and to experience counselling services as accessible. Language has an important function in facilitating that understanding and healthcare professionals should be mindful of this in their interactions, and in the possible psycho-educational work they may be involved in with couples.

Provide psycho-educational function. Counselling may be the forum where couples receive the opportunity to learn even more about their fertility treatment. In so doing, healthcare professionals can think of ways for making treatment-related information readily available to patients. Information can be provided in differing formats such as information sheets, self-study material, brochures, booklets, and online resources. Predictability, control, and treatment-related perspective may assist couples to psychologically plan for their treatments and, with that, enable them to cope better with the demands of treatment.

The Limitations of My Research

As I considered my research project, I wondered to myself how I could have done things differently and how this may have shaped the outcomes. With regards to this, I explore the limitations of my research and the recommendations for future research in the area of fertility treatment experiences.

Interview Setting

I wondered to myself how interviewing the participants at the REU may have shaped their narratives. I wondered how the research may have turned out differently if I had conducted the interviews at their home, for instance, outside of the treatment venue.

Interview Media

How might the research have looked had I video-recorded the interviews? Would the non-verbal data have helped support or change the findings in any way? I would have incorporated a video recording to supplement the verbal data with non-verbal responses.

Drop-out Rate

How might the research have looked if I either recruited more participants as couples discontinued their treatment, or conversely, only worked with the data given by Mieke and



Logan as a case study, for example? The small sample size may be viewed by some readers as a limitation of this project.

360 Degree View

How might the research have looked had I conducted interviews with the staff of the REU on their views of couples' treatment experiences, since they spent more time with the couples than I did? What salient experiences would have come up there that could have possibly further supported these research findings or injected other nuances? Further insight could have been garnered on treatment experiences utilising staff feedback.

The Research Implications and Recommendations

After concluding this project, I believe now more than ever that continued research in to couples' fertility treatment experiences should be explored, especially in developing countries like South Africa. When we know more, we can do more; this may apply both pragmatically to the services offered and experienced by couples, but also to their interpersonal experiences. The more we understand about couples' contextual experiences, the more can be done to review and improve upon service delivery on an ongoing basis, both as it applies to the provision of medical care and therapeutic supportive services.

Research utilising larger samples may provide opportunities for additional insights on treatment experiences to be gathered and for generalisable findings to be established.

Researching the experiences of clinic and laboratory staff may provide insight into the experiences of those who assist couples in their quest to have a child. What aspects shape their experiences of the work that they do daily?

Conclusion

The formalities of this thesis closed with a discussion of the findings of my research project. As I discussed the findings, I shared how and why I conducted the research in the first place, what I found, and how this answered the research question. I explored the contribution my research has made to psychology and what the implications of the findings have for both practice and future research; and in so doing, I identified the limitations of my research. I conclude my story in the prologue that follows.



EPILOGUE: US

This research process has come full circle. What I have come to realise as I take a moment to contemplate it all, is that some of the aspects of my research experiences are reminiscent of those I encountered when we were accessing fertility treatment. Mirroring the exhilaration and relief that marked the end of our fertility treatment chapter, I reconnect with those feelings, but a little differently now. Here, the most obvious reflection, I think, is the exhilaration I feel having seen the project through to completion and the accompanying relief that comes with having it documented. On a slightly more subtle note though, the exhilaration and relief are also in knowing that I have assisted others in telling their treatment stories and in doing so, helping others to get the support they require to shoulder the weighted parts of their treatment process. The arduous physical, emotional, and interpersonal challenges of enduring treatment mirror what went into compiling this document which required hours of contemplation, reading, and focus which was far from comfortable at the best of times.

I see now, as I reflect on the chapters in my thesis and the songs I open the chapters with, how these simultaneously speak to participants' experiences and capture my experiences at the same time. Being a researcher meant that I entered the context of the participants, not only during the interview process. It meant that the analysis and write-up, too, included me providing a compilation of the unique aspects of my infertility and research journeys. The vulnerabilities that come with that are all too familiar. But this time around, instead of hiding behind a magazine pretending to read it, I smile because this document replaces that magazine in more ways than one. Instead of coping by hiding behind a publication, my thesis symbolises how I turned things around. Although initiating this project was not driven by that at all, it is a surprising twist. And, I like that!



REFERENCES

- Abbey, A. (2000). Adjusting to infertility. In J. H. Harvey & E. D. Miller (Eds.), Loss and trauma: General and close relationship perspectives (pp. 331-341). New York, NY: Routledge.
- Agboghoroma, C. O., & Giwa-Osagie, O. F. (2012). Management of infertility in HIV infected couples: A review. *African Journal of Reproductive Health*, *16*, 13-20.
- Agostini, F., Monti, F., De Pascalis, L., Paterlini, M., La Sala, G. B., & Blickstein, I. (2011). Psychosocial support for infertile couples during assisted reproductive technology treatment. *Fertility and Sterility*, 95(2), 707-710. doi:10.1016/j.fertnstert.2010.06.011
- Andersen, N. A., & Erb, K. (2006). Register data on assisted reproductive technology (ART) in Europe including a detailed description of ART in Denmark. *International Journal of Andrology*, 29, 12-16. doi: 10.1111/j/1365-2605.2005.00577.x
- Anderson, K. M., Sharpe, M., Rattray, A., & Irvine, D. S. (2003). Distress and concerns in couples referred to a specialist infertility clinic. *Journal of Psychosomatic Research*, 54(4), 353-355.
- Ardenti, R., Campari, C., Agazzi, L., & La Sala, G. B. (1999). Anxiety and perceptive functioning of infertile women during in-vitro fertilization: Exploratory survey of an Italian sample. *Human Reproduction*, 14(12), 3126-3132.
- Babbie, E., & Mouton, J. (2006). The practice of social research. Cape Town, South Africa: Oxford University Press.
- Baluch, B., Nasseri, M., & Aghssa, M. M. (1998). Psychological and social aspects of male infertility in a male dominated society. *Journal of Social and Evolutionary Systems*, 21(1), 113-120.
- Bambra, C. S. (1999). Current status of reproductive behaviour in Africa. *Human Reproduction*, 5(1), 1-20. doi: 10.1093/humupd/5.1.1
- Barden-O'Fallon, J. (2005). Associates of self-reported fertility status and infertility treatment-seeking in a rural district of Malawi. *Human Reproduction*, 20(8), 2229-2236.
- Barker, C., Pistrang, N., & Elliot, R. (2002). Research methods in clinical psychology: An introduction for students and practitioners (2nd ed.). Chichester, England: John Wiley & Sons, Ltd.
- Barnes, L. W. (2014). *Conceiving masculinity: Male infertility, medicine, and identity*. Temple University Press.



- Becker, G., Castrillo, M., Jackson, R., & Nachtigall, R. D. (2006). Infertility among lowincome Latinos. *Fertility and Sterility*, *85*(4), 882-887.
- Beckman, L. J., & Harvey, S. M. (2005). Current reproductive technologies: Increased access and choice? *Journal of Social Issues*, *61*(1), 1-20.
- Belonoschkin, B. (1962). Psychosomatic factors and matrimonial infertility. *International Journal of Fertility*, 7, 29-36.
- Benedek, T. (1952). Infertility as a psychosomatic defence. *Fertility and Sterility*, *3*(6), 527-541.
- Berg, B. J., Wilson, J. F., & Weingartner, P. J. (1991). Psychological sequelae of infertility treatment: The role of gender and sex-role identification. *Social Science & Medicine*, 33(9), 1071-1080.
- Berry, D. (2005). Methodological pitfalls in the study of religiosity and spirituality. *Western Journal of Nursing Research*, *27*(5), 628-647.
- Berryman, G., Buckland, J., Champion, W., & Martin, C. (2002). The Scientist. *A Rush ofBlood to the Head* [CD]. London, England: Parlophone.
- Beutel, M., Kupfer, J., Kirchmeyer, P., Kehde, S., Köhn, F. M., Schroeder-Printzen, I., Weidner, W. (1999). Treatment-related stresses and depression in couples undergoing assisted reproductive treatment by IVF or ICSI. *Andrologia*, 31(1), 27-35.
- Biggerstaff, D., & Thompson, A. R. (2008). Interpretive Phenomenological Analysis (IPA): A qualitative methodology of choice in healthcare research. *Qualitative Research in Psychology*, 5(3), 214-224. doi: 10.1080/14780880802314304.
- Birenbaum-Carmeli, D. (2004). 'Cheaper than a newcomer': On the social production of IVF policy in Israel. *Sociology of Health & Illness*, *26*(7), 897-924.
- Bitler, M., & Schmidt, L. (2006). Health disparities and infertility: Impacts of state-level insurance mandates. *Fertility and Sterility*, *85*(4), 858-865.
- Blenner, J. L. (1990). Passage through infertility treatment: A stage theory. *Image: Journal of Nursing Scholarship*, 22(3), 153-158.
- Blumer, H. (1969). Symbolic interactionism: Perspective and method. Los Angeles, California: University of California Press.
- Boivin, J., & Kentenich, H. (Eds.). (2002). Guidelines for counselling in infertility. ESHRE Monographs. London, England: Oxford University Press.
- Boivin, J., Shoog-Svanberg, A., Andersson, L., Hjelmstedt, A., Bergh, T., & Collins, A. (1998). Distress level in men undergoing intracytoplasmic sperm injection versus invitro fertilization. *Human Reproduction*, 13(5), 1403-1406.



- Bos, H., Van Balen, F., & Visser, A. (2005). Social and cultural factors in infertility and childlessness. *Patient Education and Counseling*, *59*(3), 223-225.
- Botha, W. (1985). *A married couple with psychogenic infertility: A psychodynamic case study* (Unpublished master's thesis). University of Pretoria, South Africa. Retrievedfrom http://upetd.up.ac.za.
- Boyd, B. C., Einziger, M. A., Katunich, A., Pasillas Ii, J. A., & Kilmore, C. E. (2000). Drive. On *Make Yourself* [CD]. Los Angeles, CA: Epic, Immortal Records.
- Bresnick, E., & Taymor, M. L. (1979). The role of counseling in infertility. *Fertility and Sterility*, *32*(2), 154-156.
- Brocki, J. M., & Wearden, A. (2006). A critical evaluation of the use of Interpretive Phenomenological Analysis (IPA) in health psychology. *Psychology and Health*, 21(1), 87-108. doi: 10.1080/14768320500230185.
- Bronfenbrenner, U. (1994). Ecological models of human development. In P. Peterson, E.
 Baker, & B. McGaw (Eds.), *International Encyclopedia of Education*, (pp. 1643-1647).
 Oxford, England: Elsevier Sciences, Ltd
- Bronfenbrenner, U. (2005). *Making human being human: Bioecological perspectives on human development*. Thousand Oaks, CA: Sage.
- Brothers, S. C., & Maddux, J. E. (2003). The goal of biological parenthood and emotional distress from infertility: Linking parenthood to happiness. *Journal of Applied Social Psychology*, 33(2), 248-262.
- Brown, G. S. (2015, 8 October). Incredible story behind photo of baby surrounded by syringes. *ABC News*. Retrieved from: http://abcnews.go.com.
- Brucker, P. S., & McKenry, P. C. (2004). Support from health care providers and the psychological adjustment of individuals experiencing infertility. *Journal of Obstetric, Gynecologic, & Neonatal Nursing*, 33(5), 597-603.
- Bunting, L., & Boivin, J. (2007). Decision-making about seeking medical advice in an internet sample of women trying to get pregnant. *Human Reproduction*, 22(6), 1662-1668.
- Burns, L. H. (1987). Infertility as boundary ambiguity: One theoretical perspective. *Family Process*, *26*(3), 359-372.
- Burns, L. H., & Covington, S. N. (1999). Psychology of infertility. In S. N. Covington & L.
 H. Burns (Eds.), *Infertility counselling: A comprehensive handbook for clinicians* (pp. 1-10). New York, NY: Cambridge University Press.



- Carey, M., & Russel, S. (2003). Outsider-witness practices: Some answers to commonly asked questions. *International Journal of Narrative Therapy and Community Work*, 1, 1-22.
- Carlile, B., & Hanseroth, P. (2007). The story. On The Story [CD]. Vancouver, Canada: Sony.
- Chambers, G. M., Hoang, V. P., & Illingworth, P. J. (2013). Socioeconomic disparities in access to ART treatment and the differential impact of a policy that increased consumer costs. *Human Reproduction*, 28, 3111-3117. doi: 10.1093/humrep/det302.
- Chan, M. (2015, October 9). Photo of IVF baby surrounded by heart of syringes goes viral, inspires mothers. *New York Daily News*. Retrieved from http://www.nydailynews.com.
- Chaplin, T., Hughes, R., & Rice-Oxley, T. (2004). Somewhere only we know. On *Hopes and Fears* [CD]. East Sussex, England: Island.
- Charlish, A., & Davies, K. (2007). *Natural fertility and pregnancy: Preparing for parenting the healthy way.* London, England: Hermes House.
- Chiba, H., Mori, E., Morioka, Y., Kashwakura, M., Nadaoka, T., Saito, H., & Hiroi, M. (1997). Stress of female infertility: Relations to length of treatment. *Gynecologic and Obstetric Investigation*, 43(3), 171-177.
- Colineau, N., & Paris, C. (2010). Talking about your health to strangers: Understanding the use of online social networks by patients. *New Review of Hypermedia and Multimedia*, *16*(1-2), 141-160.
- Connell, R. W. (1995). Masculinities. Cambridge: Polity Press.
- Conrad, P., & Schneider, J. W. (1980). *The medicalisation of deviance: From badness to sickness*. St Louis, MO: Mosby.
- Constitution of the Republic of South Africa Act No 108 of 1996, Chapter 2 Bill of Rights (1996). Retrieved from www.gov.za.
- Coulson, C., & Jenkins, J. (2005). Complementary and alternative medicine utilisation in NHS and private clinic settings: A United Kingdom survey of 400 infertility patients. *Journal of Experimental & Clinical Assisted Reproduction*, 2(1), 5. doi: 10.1186/1743-1050-2-5.
- Cousineau, T. M., & Domar, A. D. (2007). Psychological impact of infertility. *Best Practice & Research Clinical Obstetrics & Gynaecology*, 21(2), 293-308. doi: 10.1016/j.bpobgyn.2006.12.003.
- Covington, S. N. (1995). The role of the mental health professional in reproductive medicine. *Fertility and Sterility*, *64*(5), 895-897.



- Covington, S. N., & Burns, L. H. (Eds.). (2006). *Infertility counseling: A comprehensive handbook for clinicians*. New York, NY: Cambridge University Press.
- Crawshaw, M. A., & Sloper, P. (2010). "Swimming against the tide" The influence of fertility matters on the transition to adulthood or survivorship following adolescent cancer. *European Journal of Cancer Care, 19*(5), 610-620. doi: 10.1111/j.1365-2354. 2009.01118.x
- Creswell, J. W., & Clark, V. L. (2011). *Designing and conducting mixed methods research* (2nd ed.). Thousand Oaks, CA: Sage.
- Culley, L., Hudson, N., Lanoil, J., & Fisher, C. (2007). Public understandings of science:
 British South Asian men's perceptions of third party assisted conception. *International Journal of Interdisciplinary Social Sciences*, 2(4), 279-286.
- Daar, A. S., & Merali, Z. (2002). Infertility and social suffering: The case of ART in developing countries. In E. Vayena, P. J. Rowe, & P. D. Griffin (Eds.), *Current practices and controversies in assisted reproduction* (pp. 15-21). Geneva, Switzerland: World Health Organization [WHO].
- Dahl, R. (1991). The Minpins. United Kingdom: Jonathan Cape.
- Daly, I., & Bewley, S. (2013). Reproductive ageing and conflicting clocks: King Midas' touch. *Reproductive BioMedicine Online*, 27, 722-732. doi: 10.1016/j.rbmo.2013.09.012.
- Daly, K. J. (1999). Crisis of genealogy: Facing the challenges of infertility. In H. I. McCubbin (Ed.), *The dynamics of resilient families*, (pp. 1-39). Thousand Oaks, CA: Sage Publications.
- Dancet, E. A. F., Van Empel, I. W. H., Rober, P., Nelen, W. L. D. M., Kremer, J. A. M., & d'Hooghe, T. M. (2011). Patient-centred infertility care: A qualitative study to listen to the patient's voice. *Human Reproduction*, 0(0), 1-7.doi:10.1093/humrep/der022.
- Daniluk, J. C. (2001). Reconstructing their lives: A longitudinal, qualitative analysis of the transition to biological childlessness for infertile couples. *Journal of Counseling andDevelopment*, 79(4), 439 -449.
- Demouzon, J., & Logerotlebrun, H. (1992). Evaluation of infertility therapy: Epidemiological considerations. *Contraception Fertilite Sexualite*, 20(2), 142-158. Retrieved from http://0apps.webofknowledge.com.
- Department of Health (2009). *Regulated fertility services: A commissioning aid*. Retrieved from http://www.dh.gov.uk.
- Diamond, R., (Ed.). (1999). Couple therapy for infertility. New York, NY: Guilford Press.



- Domar, A. D., Zuttermeister, P. C., & Friedman, R. (1993). The psychological impact of infertility: A comparison with patients with other medical conditions. *Journal of Psychosomatic Obstetrics and Gynaecology*, 14, 45-45.
- Dowling, M. (2007). From Husserl to van Manen: A review of different phenomenological approaches. *Journal of Nursing Studies*, 44(1), 131-142. doi: 10.1016/j.ijnurstu.2005.11.026.
- Dukes, S. (1984). Phenomenological methodology in the human sciences. *Journal of Religion* and Health, 3, 197-203. doi: 10.1007/BF00990785.
- Dunson, D. B., Baird, S. D., & Colombo, B. (2004). Increased infertility with age in men and women. Obstetrics and Gynaecology, 103, 51-56. doi: 10.1097/01.AOG.0000100153.24061.45.
- Dyer, S. J., & Kruger, T. F. (2012). Assisted reproductive technology in South Africa: First results generated from the South African Register of Assisted Reproductive Techniques. SAMJ: South African Medical Journal, 102(3), 167-170.
- Dyer, S. J., Abrahams, N., Hoffman, M., & Van der Spuy, Z. M. (2002). Infertility in South Africa: Women's reproductive health knowledge and treatment-seeking behaviour for involuntary childlessness. *Human Reproduction*, 17(6), 1657-1662. doi: 10.1093/humrep/17.6.1657.
- 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 treatmentseeking behaviour among men suffering from couple infertility in South Africa. *Human Reproduction*, 19(4), 960-967. doi: 10.1093/humanrep/deh195.
- 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.
 doi:10.1093/humanrep/deh845.
- Dyer, S. J., Lombard, C., & Van der Spuy, Z. (2009). Psychological distress among men suffering from couple infertility in South Africa: A quantitative assessment. *Human Reproduction*, 24(11), 2821-2826. doi: 10.1093/humrep/dep278.
- Dyer, S. J., Mokoena, N. E., Maritz, J., & Van der Spuy, Z. M. (2008). Motives for parenthood among couples attending a level 3 infertility clinic in the public health sector in South Africa. *Human Reproduction*, 23(2), 352-357. doi: 10.1093/humanrep/dem279.



- Easton, K. L., McComish, J. F., & Greenberg, R. (2000). Avoiding common pitfalls in qualitative data collection and transcription. *Qualitative Health Research*, 10, 703 - 707. doi: 10.1177/104973200129118651.
- Eatough, V., & Smith, J. A. (2006). I feel like scrambled egg in my head: An idiographic case study of meaning making and anger using interpretive phenomenological analysis. *Psychology and Psychotherapy: Theory, Research and Practice*, 79(1), 115-135.
- Eatough, V., & Smith, J.A. (2008). Interpretive Phenomenological Analysis. In C. Willig & W. Stainton-Rogers (Eds.). *The Sage handbook of qualitative research in Psychology*, London, England: Sage.
- Edelmann, R. J., & Connolly, K. J. (1998). Psychological state and psychological strain in relation to infertility. *Journal of Community & Applied Social Psychology*, 8(4), 303-311.
- Engel, G. L. (1989). The need for a new medical model: A challenge for biomedicine. *Holistic Medicine*, *4*(1), 37-53.
- Epstein, Y. M., Rosenberg, H. S., Grant, T. V., & Hemenway, N. (2002). Use of the internet as the only outlet for talking about infertility. *Fertility and Sterility*, 78(3), 507-514.
- Esteves, S. C., Miyaoka, R., & Agarwal, A. (2011). An update on the clinical assessment of the infertile male. *Clinics*, *66*, 691-700. doi: 10.1590/S1907-59322011000400026.
- Eugster, A., & Vingerhoets, A. J. J. M. (1999). Psychological aspects of in vitro fertilization: A review. Social Science & Medicine, 48(5), 575-589.
- Fathalla, M.F. (2001). Current challenges in assisted reproduction. In E. Vayena, P. J. Rowe,
 & P. D. Griffin (Eds.), *Current practices and controversies in assisted reproduction: Report of a meeting on "Medical, Ethical and Social Aspects of Assisted Reproduction"*.
 Paper presented at WHO Headquarters in Geneva, Switzerland.
- Feinberg, E. C., Larsen, F. W., Catherino, W. H., Zhang, J., & Armstrong, A. Y. (2006).
 Comparison of assisted reproductive technology utilization and outcomes between
 Caucasian and African American patients in an equal-access-to-care setting. *Fertility* and Sterility, 85(4), 888-894.
- Feinberg, E. C., Larsen, F. W., Wah, R. M., Alvero, R. J., & Armstrong, A. Y. (2007). Economics may not explain Hispanic underutilization of assisted reproductive technology services. *Fertility and Sterility*, 88(5), 1439-1441.



Feldman-Savelsberg, P. (2002). Is infertility an unrecognised public health and population problem? The view from the Cameroon grassfields. In M. C. Inhorn, & F. Van Balen. (Eds.), *Infertility around the globe: New thinking on childlessness, gender and reproductive technologies: A view from the social sciences* (pp.215-231). Berkeley, CA: University of California Press.

Finlay, L., & Gough, B. (Eds.). (2003). Reflexivity. Oxford, England: Blackwell Science.

Fischer, I. C. (1953). Psychogenic aspects of infertility. Fertility and Sterility, 4(6), 466-471.

- 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. doi: 10.1038/aja.2011.72
- Folkvord, S., Odegaard, O. A., & Sundby, J. (2005). Male infertility in Zimbabwe. *Patient Education and Counseling*, 59(3), 239-243.
- Fourie, F. L., Botes, A. D., & Van der Merwe, J. V. (1988). Cost analysis study of an in vitro fertilisation programme. *South African Medical Journal*, 73(2), 120-122.
- Gabrino, J. (1982). *Children and families in the social environment*. New York, NY: Aldine Publishing.
- Gamolina, J. [Online image]. (n.d.). Retrieved April 9, 2017 from www.pinterest.com
- Gannon, K., Glover, L., & Abel, P. (2004). Masculinity, infertility, stigma and media reports. *Social Science & Medicine*, *59*(6), 1169-1175.
- Gibson, D. M., & Myers, J. E. (2002). The effect of social coping resources and growthfostering relationships on infertility stress in women. *Journal of Mental Health Counseling*, 24(1), 68.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, New Jersey: Prentice-Hall.
- Gonzalez, L. O. (2000). Infertility as a transformational process: A framework for psychotherapeutic support of infertile women. *Issues in Mental Health Nursing*, 21(6), 619-633. doi: 10.1080/01612840050110317.
- Gough, B. (2016). Men's depression talk online: A qualitative analysis of accountability and authenticity in help-seeking and support formulations. *Psychology of Men & Masculinity*, 17(2), 156-164.
- Gravett, I. (2008). *Narratives of couples affected by infertility: Daring to be fruitful* (Doctoral dissertation). University of Pretoria, South Africa. Retrieved from http://upetd.up.ac.za.



- Greil, A. L. (1991). Not yet pregnant: Infertile couples in contemporary America. New Brunswick, NJ: Rutgers University Press.
- Greil, A. L. (1997). Infertility and psychological distress: A critical review of the literature. *Social Science and Medicine*, *45*(11), 1679-1704.
- Greil, A. L., & McQuillan, J. (2004). Help-seeking patterns among subfecund women. Journal of Reproductive and Infant Psychology, 22(4), 305-319.
- Greil, A. L., McQuillan, J., Benjamins, M., Johnson, D. R., Johnson, K. M., & Heinz, C. R. (2010). Specifying the effects of religion on medical helpseeking: The case of infertility. *Social Science & Medicine*, *71*(4), 734-742. doi: 10.1016/j.socscimed.2010.04.033.
- Greil, A. L., Slauson-Blevins, K., & McQuillan, J. (2010). The experience of infertility: A review of recent literature. *Sociology of Health & Illness*, *32*(1), 140-162.
- Grimes, D. A., Benton, J., Singh, S., Romero, M., Ganatra, B., Okonofua, F. E., & Shah, I. H.
 (2006). Unsafe abortion: The preventable pandemic. *TheLancet Sexual and Reproductive Health Series*, 238, 1908 -1919.
- Gurunath, S., Pandian, Z., Anderson, R. A., & Bhattacharya, S. (2011). Defining infertility: A systematic review of prevalence studies. *Human Reproductive Update*, *17*, 578-588. doi: 10.1093/humupd/dmr015.
- Hames, I. (2007). Peer review and manuscript management in scientific journals: Guidelines for good practice. Oxford, England: Blackwell.
- Hammarberg, K., & Kirkman, M. (2013). Infertility in resource-constrained settings: Moving towards amelioration. *Reproductive BioMedicine Online*, 26(2), 189-195. doi: 10. 1016/j.rbmo.2012.11.009.
- Handwerker, L. (2002). The politics of making modern babies in China: Reproduction technologies and the "new" eugenics. In M. C. Inhorn & F. Van Balen (Eds.), *Infertility around the globe: New thinking on childlessness, gender and reproductive technologies: A view from the social sciences* (pp. 298-311). Berkeley, CA: University of California Press.
- Hanna, E., & Gough, B. (2016). Emoting infertility online: A qualitative analysis of men's forum posts. *Health*, 1-28. doi: 1363459316649765.
- Hansell, P. L., Thorn, B. E., Prentice-Dunn, S., & Floyd, D. L. (1998). The relationships of primary appraisals of infertility and other gynecological stressors to coping. *Journal of Clinical Psychology in Medical Settings*, 5(2), 133-145.



- Harvey, J. H. (2002). Disenfranchised grief: New directions, challenges and strategies for practice. Champaign, Illinois: Research Press.
- Hassan, M. A., & Killick, S. R. (2003). Effect of male age on fertility: Evidence for the decline in male fertility with increasing age. *Fertility and Sterility*, 79, 1520-1527.

Heidegger, M. (1962). Being and time. Oxford, England: Blackwell.

- Henne, M. B., & Bundorf, M. K. (2008). Insurance mandates and trends in infertility treatments. *Fertility and Sterility*, 89(1), 66-73.
- Henning, E., Van Rensburg, W., & Smit, B. (2004). *Finding your way in qualitative research*. Pretoria, South Africa: Van Schaik.
- Henning, K., Strauss, B., & Strauss, B. (2002). *Psychological and psychosomatic aspects of involuntary childlessness: State of research at the end of the 1990s*. Ashland, OH: Hogrefe and Huber.
- Heywood, M. (2009). South Africa's treatment action campaign: Combining law and social mobilization to realize the right to health. *Journal of Human Rights Practice*, 1(1), 14-36.
- Hjelmstedt, A., Andersson, L., Skoog-Svanberg, A., Bergh, T., Boivin, J., & Collins, A. (1999). Gender differences in psychological reactions to infertility among couples seeking IVF-and ICSI-treatment. *Acta Obstetricia Et Gynecologica Scandinavica*, 78(1), 42-49.
- Hlatshwayo, S. (2004). Infertility among black South African women. *Agenda*, *18*(60), 146-154.
- Hollos, M. (2003). Profiles of infertility in southern Nigeria: Women's voices from Amakiri. *African Journal of Reproductive Health*, 7(2), 46-56.
- Holter, H., Anderheim, L., Bergh, C., & Möller, A. (2006). First IVF treatment Short-term impact on psychological well-being and the marital relationship. *Human Reproduction*, 21(12), 3295-3302.
- Holter, H., Anderheim, L., Bergh, C., & Möller, A. (2007). The psychological influence of gender infertility diagnoses among men about to start IVF or ICSI treatment using their own sperm. *Human Reproduction*, 22(9), 2559-2565.
- Huyser, C., & Boyd, L. (2012). Assisted reproduction laboratory cost-drivers in South Africa:Value, virtue and validity. *Obstetrics and Gynaecology Forum*, 22, 15-21.
- Huyser, C., & Boyd, L. (2013). ART in South Africa: The price to pay. *Facts, Views and Vision in Obgyn*, 5(2), 91-99.



- Huyser, C., & Fourie, J. (2010). SPERM ONLY PLEASE: Prevention of infections in an assisted reproduction laboratory in a developing country. *Facts, Views and Vision in Obgyn*, 97-106.
- Inhorn, M. C. (1994). Kabsa (aka mushāhara) and threatened fertility in Egypt. *Social Science & Medicine*, *39*(4), 487-505.
- Inhorn, M. C. (2002). The "local" confronts the "global": Infertile bodies and the new reproductive technologies in Egypt. In M. C. Inhorn & F. Van Balen (Eds.), *Infertility* around the globe: New thinking on childlessness, gender, and reproductive technologies: A view from the social sciences (pp. 263-282). Los Angeles, CA: University of California Press.
- Inhorn, M. C. (2003). "The worms are weak": Male infertility and patriarchal paradoxes in Egypt. *Men and Masculinities*, 5(3), 236-256.
- Inhorn, M. C., & Fakih, M. H. (2005). Arab Americans, African Americans, and infertility: Barriers to reproduction and medical care. *Fertility and Sterility*, *85*(4), 844-852.
- Ireland, M. S. (1993). *Reconceiving women: Separating motherhood from female identity*. Guilford Press.
- Jain, T. (2006). Socioeconomic and racial disparities among infertility patients seeking care. *Fertility and Sterility*, 85(4), 876-881.
- Jennings, P. K. (2010). "God had something else in mind": Family, religion, and infertility. *Journal of Contemporary Ethnography*, 39(2), 215-237. doi: 10.1177/0891241609342432.
- Johansson, M., & Berg, M. (2005). Women's experiences of childlessness 2 years after the end of in vitro fertilization treatment. *Scandinavian journal of caring sciences*, *19*(1), 58-63.
- Jordan, C., & Revenson, T. A. (1999). Gender differences in coping with infertility: A metaanalysis. *Journal of Behavioral Medicine*, 22(4), 341-358.
- Kantor, B. (2006). A Foucauldian discourse analysis of South African women's experience of involuntary childlessness (Doctoral dissertation). University of the Western Cape, South Africa.
- Kielman, K. (1998). Barren ground: Contesting identities of infertile women in Pemba,
 Tanzania. In M. Lock & P. A. Kaufert (Eds.), *Pragmatic women and body politics* (pp. 127-163). Cambridge, MA: Cambridge University Press.
- Kikendall, K. A. (1994). Self-discrepancy as an important factor in addressing women's emotional reactions to infertility. *Professional Psychology: Research and Practice*, 25(3), 214-220. doi: 10.1037/0735-7028.25.3.214



- King, R. B. (2003). Subfecundity and anxiety in a nationally representative sample. *Social Science and Medicine*, *56*(4), 739-751.
- Kirkman, M. (2001). Thinking of something to say: Public and private narratives of infertility. *Health Care for Women International*, 22(6), 523-535.
- Kirkman, M., & Rosenthal, D. (1999). Representations of reproductive technology in women's narratives of infertility. *Women and Health*, *29*(2), 17-36.
- Kongos, J. (2012). Come with me now. On *Lunatics* [CD]. Phoenix, Arizona: Tokoloshe Records.
- Kraut, R., Patterson, M., Lundmark, V., Kiesler, S., Mukophadhyay, T., & Scherlis, W. (1998). Internet paradox: A social technology that reduces social involvement and psychological well-being? *American Psychologist*, *53*(9), 1017-1031.
- Krefting, R. (1991). Rigor in qualitative research: The assessment of trustworthiness. *The American Journal of Occupational Therapy*, *4*, 214-222.
- Krishnan, V. (2010, May). Early childhood development: A conceptual model. Paper presented at the Early Childhood Council Annual Conference 2010 on "Valuing Care", Christchurch, New Zealand.
- Kruger, T. F., Van Schouwenburg, J. A. M. H., Stander, F. S. H., Van den Heever, A. D., Van Zyl, J. A., Menkveld, R., Kopper, K., De Villiers, A., Conradie, E., Odendaal, H. J., & De Villiers, J. N. (1985). Results of Phase I of the in vitro fertilization and embryo transfer programme at Tygerberg Hospital. *South African Medical Journal*, *67*, 751-753.
- Küchenhoff, J. (1999). Unfulfilled desire for children: What is the grief for men? *Therapeutische Umschau. Revue Therapeutique*, *56*(5), 260-264.
- Kunkle, D., & Cooperman, G. (2007, July). Twenty-six moves suffice for Rubik's cube. Proceedings of the 2007 International Symposium on Symbolic and Algebraic Computation (pp. 235-242). doi:10.1145/1277548.1277581.
- Kurtz, G. (Producer), & Kershner, I. (Director). (1980). Star Wars: Episode V The Empire Strikes Back [Motion picture]. Unites States of America: Lucasfilm Ltd.
- Kurzweg, J., Marshall, B. A., Phillips, S. T., Stapp, S. A., & Tremonti, M. T. (1999). Are you ready? On *Human Clay* [CD]. Europe, Austria: Wind-Up Entertainment, Inc.
- Lamar, C. A., & De Cherney, A. H. (2009). Fertility preservation: State of the science and future research directions. *Fertility and Sterility*, 91(2), 316-319.doi: 10.1016/j.fertnstert.2008.08.133.



- Langdridge, D. (2007). *Phenomenological psychology: Theory, research and method.* Harlow, England: Pearson Education.
- Larsen, U. (2009). Primary and secondary infertility in sub-Saharan Africa. *International Journal of Epidemiology*, 29, 285-291.
- Lawler, J. (1998). Phenomenologies as research methodologies for nursing: From philosophy to researching practice. *Journal of Clinical Nursing*, *5*, 104-111.
- LeCompte, M. D., Klinger, J. K., Campbell, S. A., & Menke, D. W. (2003). Editor's introduction. *Review of Educational Research*, 73(2), 123-124.
- Lee, T. Y., Sun, G. H., & Chao, S. C. (2001). The effect of an infertility diagnosis on the distress, marital and sexual satisfaction between husbands and wives in Taiwan. *Human Reproduction*, *16*(8), 1762-1767.
- Leke, R. J. I., Oduma, J. A., Bassol-Mayagoitia, S., Bacha, A. M., & Grigor, K. M. (1993). Regional and geographical variations in infertility: Effects of environmental, cultural and socioeconomic factors. *Environmental Health Perspectives*, 101, 73-80.
- Leon, I. G. (1990). *When a baby dies: Psychotherapy for pregnancy and newborn loss*. New Haven, Connecticut: Yale Press.
- Letherby, G. (2002). Childless and bereft? Stereotypes and realities in relation to "voluntary" and "involuntary" childlessness and womanhood. *Sociological Inquiry*, *72*(1), 7-20.
- Li, Y., Lin, H., Li, Y., & Cao, J. (2011). Association between socio-psycho-behavioural factors and male semen quality: Systematic review and meta-analyses. *Fertility and Sterility*, 95, 116-123. doi: 10.1016/j.fertnstert.2010.06.031
- Lok, I. H., Lee, D. T. S., Cheung, L. P., Chung, W. S., Lo, W. K., & Haines, C. J. (2002). Psychiatric morbidity amongst infertile Chinese women undergoing treatment with assisted reproductive technology and the impact of treatment failure. *Gynecologic and Obstetric Investigation*, 53(4), 195-199.
- Lopez, K. (2004). Descriptive versus interpretive phenomenology. *Journal of Qualitative Health Research*, *5*, 726-735.
- Lukse, M. P., & Vacc, N. A. (1999). Grief, depression and coping in women undergoing infertility treatment. *Obstetrics Gynecology*, 93(2), 245-251.
- Luft, J., & Ingham, H. (1961). The Johari Window. *Human Relations Training News*, 5(1), 6-7.



- Luna, F. (2002). Assisted reproductive technology in Latin America: Some ethical and sociocultural issues. In E. Vayena, P. J. Rowe, & P. D. Griffin (Eds.), *Current practices* and controversies in assisted reproduction (pp. 31-40). Geneva, Switzerland: World Health Organization (WHO).
- Mabasa, L. F. (2003). *The psychological impact of infertility on African women and their families* (Unpublished doctoral dissertation). University of South Africa, South Africa.
- Mackey, S. (2005). Phenomenological nursing research: Methodological insights derived from Heidegger's interpretive phenomenology. *Journal of Nursing Studies*, *42*, 179-186.
- Madill, A., Jordan, A., & Shirley, C. (2000). Objectivity and reliability in qualitative analysis:
 Realist, contextualist and radical constructionist epistemologies. *British Journal of Psychology*, *91*, 1-20.
- Mahajan, N. N. (2008). *Biopsychosocial associates of infertility related distress and treatment outcomes* (Unpublished doctoral dissertation). University of Adelaide, Australia.
- Mahajan, N. N., Turnbull, D. A., Davies, M. J., Jindal, U. N., Briggs, N. E., & Taplin, J. E. (2009). Adjustment to infertility: The role of intrapersonal and interpersonal resources/vulnerabilities. *Human Reproduction*, 24(4), 906-912.
- Malpani, A., & Malpani, A. (1992). Simplifying assisted conception techniques to make them universally available: A view from India. *Human Reproduction*, *7*, 49-50.
- Marchbanks, P. A., Petersen, H. B., & Rubin, G. L. (1989). Research on infertility: Definition makes a difference. *American Journal of Epidemiology*, *130*, 259-267.
- Maree, J. G. (2013). *Counselling for career construction: Connecting life themes to construct life portraits. Turning pain in to hope.* Rotterdam, The Netherlands: Sense.
- Marsh, M., & Ronner, W. (1996). *The empty cradle: Infertility in America from colonial times to the present*. Baltimore, MD: Johns Hopkins University Press.
- Mascarenhas, M. N., Flaxman, S. R., Boerma, T., Vanderpoel, S., & Stevens, G. A. (2012).
 National, regional, and global trends in infertility prevalence since 1990: A systematic analysis of 277 health surveys. *PLoS Med*, 9(12), 1-12. doi: 10.1371/journal.pmed.1001356.
- Matthews, R., & Matthews, A. M. (1986). Infertility and involuntary childlessness: The transition to nonparenthood. *Journal of Marriage and the Family*, *48*(3): 641-649.
- 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.



- McQuillan, J., Stone, R. A. T., & Greil, A. L. (2007). Infertility and life satisfaction among women. *Journal of Family Issues*, *28*(7), 955-981.
- Meirow, D., &Schenker, J. G. (1997). The current status of sperm donation in assisted reproductive technology: Ethical and legal considerations. *Journal of Assisted Reproduction and Genetics*, 14(3), 133-138.
- Menning, B. E. (1980). The emotional needs of infertile couples. *Fertility and Sterility*, *34*(4), 313-319.
- Meyer, M. K. (2001). *Coping styles of women experiencing infertility* (Doctoral dissertation). Retrieved from http://etd.ohiolink.edu.
- Miall, C. E. (1985). Perceptions of informal sanctioning and the stigma of involuntary childlessness. *Deviant Behavior*, *6*(4), 383-403.
- Mitchell, A. A. (2002). Infertility treatment More risks and challenges. *The New England Journal of Medicine*, *346*(10), 769-770.
- Moges, A. (2003, September). *FGM Myths and justifications*. Paper presented at the Eighth International Metropolis Conference, Vienna. Retrieved fromwww.african-women.org
- Mohsen, V., Smith, D. R., & Ping-Chi, H. (2011). How does lead induce male infertility? *Iranian Journal of Reproductive Medicine*, 9, 1-8.
- Molock, S. D. (1999). Racial, cultural, and religious issues in infertility counseling. In L. H.
 Burns & S. N. Covington (Eds.), *Infertility counseling: A comprehensive handbook for clinicians* (pp. 249–265). New York: The Parthenon Publishing Group.
- Mondal, S. K. (2013). Histopathologic analysis of female genital tuberculosis: A fifteen-year retrospective study of 110 cases in eastern India. *Turkish Journal of Pathology*, 1, 41-45. doi: 10.5146/tjpath.2013.01146.
- 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.
- Morakinyo, A. O., Iranloye, B. O., Daramola, A. O., & Adegoke, O. A. (2011). Antifertility effect of calcium channel blockers on male rats: Association with oxidative stress. *Advances in Medical Science*, *56*, 95-105. doi: 10.2478/v10039-011-0018-y.
- Moran, D. (2000). Introduction to Phenomenology. London, England: Routledge.
- Morris, M. W., Leung, K., Ames, D., & Lickel, B. (1999). Views from inside and outside: Integrating emic and etic insights about culture and justice judgment. Academy of Management Review, 24(4), 781-796.



- Nachtigall, R. D. (2006). International disparities in access to infertility services. *Fertility and Sterility*, *85*(4), 871-875.doi: 10.1016/j.fertnstert.2005.08.066.
- Nachtigall, R. D., Tschann, J. M., Quiroga, S. S., Pitcher, L., & Becker, G. (1997). Stigma, disclosure, and family functioning among parents with children conceived through donor insemination. *Fertility and Sterility*, 68(1), 83-89.
- Nahar, P. (2007). *Childless in Bangladesh: Suffering and resilience among rural and urban women* (Doctoral thesis). University of Amsterdam, Amsterdam. Retrieved from http://dare.uva.nl
- Nahar, P., Sharma, A., Sabin, K., Begum, L., Ahsan, S. K., & Baqui, A. H. (2000). Living with infertility: Experiences among urban slum populations in Bangladesh. *Reproductive Health Matters*, 8(15), 33-44.
- Ndowa, F., Lusti-Narasimhan, M., & Unemo, M. (2012). The serious threat of multidrugresistant and untreatable gonorrhoea: The pressing need for global action to control the spread of antimicrobial resistance, and mitigate the impact on sexual and reproductive health. *Sexually Transmitted Infection*, 88(5), 317-318. doi: 10.1136/sextrans-2012-050674.
- Negro-Vilar, A. (1993). Stress and other environmental factors affecting fertility in men and women: Overview. *Environmental Health Perspectives Supplements*, *101*(2), 59-64.
- Neuman, W. L. (2000). *Social research methods: Qualitative and quantitativeapproaches* (4th ed.). Boston, MA: Allyn & Bacon.
- Nietzsche, F. W. (1978). *Thus spoke Zarathustra: A book for all and none* (W. A. Kaufmann, Trans.). New York: Penguin Books. (Original work published 1883).
- Nyboe, A. A., Andersen, A. N., & Erb, K. (2006). Register data on assisted reproductive technology (ART) in Europe including a detailed description of ART in Denmark. *International Journal of Andrology*, 29(1), 12-16.
- Oates, R. (2012). Evaluation of the azoospermic male. *Asian Journal of Andrology*, *14*, 82-87. doi:10.1038/aja.2011.60
- Oddens, B. J., Den Tonkelaar, I., & Nieuwenhuyse, H. (1999). Psychosocial experiences in women facing fertility problems - A comparative survey. *Human Reproduction*, 14(1), 255-261.
- Okonofua, F. E. (1999). Infertility and women's reproductive health in Africa. *African Journal of Reproductive Health*, *3*(1), 7-12.



- Okonofua, F. E. (1996). The case against new reproductive technologies in developing countries. *British Journal of Gynaecology and Obstetrics*, *103*, 957-962.
 doi: 10.1111/j.1471-0528.1996.tb09542.x
- Olivius, C., Friden, B., Borg, G., & Bergh, C. (2004). Why do couples discontinue in vitro fertilization treatment? A cohort study. *Fertility and Sterility*, *81*(2), 258-261.
- Olshansky, E. F. (1987). Identity of self as infertile: An example of theory-generating research. *Advances in Nursing Science*, *9*(2), 54-63.
- Ombelet, W., & Campo, R. (2007). Affordable IVF for developing countries. *Reproductive BioMedicine Online*, *15*(3), 257-265. doi: 10.1016/S1472-6483(10) 60337-9.
- Ombelet, W., Cooke, I., Dyer, S., Serour, G. I., & Devroey, P. (2008). Infertility and the provision of infertility medical services in developing countries. *Human Reproduction Update*, 14(6), 605-621. doi: 10.1093/humupd/dmn042.
- Osborne, J. (1994). Some similarities and differences among phenomenological and other methods of psychological qualitative research. *Canadian Psychological Association*, *35*, 167-189.
- Parry, D. C. (2005). Work, leisure, and support groups: An examination of the ways women with infertility respond to pronatalist ideology. *Sex Roles, 53*(5/6), 337-346.
- Pasch, L. A., & Christensen, A. (2000). Couples facing fertility problems. In K. B. Schmaling
 & T. G. Sher (Eds.), *The psychology of couples and illness: Theory, research and practice* (pp. 241-267). Washington DC: American Psychological Association.
- Pashigian, M. J. (2002). Conceiving the happy family: Infertility and marital policies in northern Vietnam. In M. C. Inhorn & F. Van Balen (Eds.), *Infertility around the globe:* New thinking on childlessness, gender, and reproductive technologies: A view from the social sciences (pp. 134-151). Berkeley, CA: University of California Press.
- Pearce, T. O. (1999). She will not be listened to in public: Perceptions among the Yoruba of infertility and childlessness in women. *Reproductive Health Matters*, 7(13), 69-79.
- Peddie, V. L., Van Teijlingen, E., & Bhattacharya, S. (2005). A qualitative study of women's decision-making at the end of IVF treatment. *Human Reproduction*, 20(7), 1944-1951.
- Pei, J., Strehler, E., Noss, U., Abt, M., Piomboni, P., Baccetti, B., & Sterzik, K. (2005). Quantitative evaluation of spermatozoa ultrastructure after acupuncture treatment for idiopathic male infertility. *Fertility and Sterility*, 84(1), 141-147.
- Pennings. G., & Ombelet, W. (2007). Coming soon to your clinic: Patient-friendly ART. *Human Reproduction*, 22(8), 2075-2079. doi: 10.1093/humrep/dem158.



- Peronace, L. A., Boivin, J., & Schmidt, L. (2007). Patterns of suffering and social interactions in infertile men: 12 months after unsuccessful treatment. *Journal of Psychosomatic Obstetrics & Gynecology*, 28(2), 105-114.
- Petraglia, F., Serour, G. I., & Chapron, C. (2013). The changing prevalence of infertility. *International Journal of Gynaecology and Obstetrics*, 123, 1-5. doi: 10.1016/jijgo.2013.09.005.
- Pfeffer, N., & Woollett, A. (1983). *The experience of infertility*. London, England: Virago Press.
- Phillips, E., Elander, J., & Montague, J. (2014). Managing multiple goals during fertility treatment: An interpretive phenomenological analysis. *Journal of Health Psychology*, 19(4), 531-543.
- Pietkiewicz, I., & Smith, J. A. (2012). Praktyczny przewodnik interpretacyjnej analizy fenomenologicznej w badaniach jakosciowych w psychologii [A practical guide to using interpretative phenomenological analysis in qualitative research psychology]. *Czasopismo Psychologiczne*, 18(2), 361-369.
- Ponterotto, J. G. (2005). Qualitative research in counselling psychology: A primer on research paradigms and philosophy of science. *Journal of Counseling Psychology*, 5(2), 126-136. doi: 10.1037/0022-0167.52.2.126.
- Provoost, V., Pennings, G., De Sutter, P., Gerris, J., Van de Velde, A., & Dhont, M. (2010).
 Patients' conceptualization of cryopreserved embryos used in their fertility treatment. *Human Reproduction*, 25(3), 705-713. doi: 10.1093/humrep/dep387.
- Puchalski, C. M., Blatt, B., Kogan, M., & Butler, A. (2014). Spirituality and health: The development of a field. *Academic Medicine*, *89*(1), 10-16.
- Randolph, J. J. (2009). A guide to writing the dissertation literature review. *Practical Assessment, Research & Evaluation, 14*(13), 1-13.
- Redshaw, M., Hockley, C., & Davidson, L. L. (2007). A qualitative study of the experience of treatment for infertility among women who successfully became pregnant. *HumanReproduction*, 22(1), 295-304.
- Reis, S., Xavier, M. R., Coelho, R., & Montenegro, N. (2013). Psychological impact of single and multiple courses of assisted reproductive treatments in couples: A comparative study. *European Journal of Obstetrics & Gynaecology and Reproductive Biology*, *171*(1), 61-66. doi: 10.1016/j.ejogrb.2013.07.034.
- Remennick, L. (2010). Childless in the land of imperative motherhood: Stigma and coping among infertile Israeli women. *Sex Roles*, *43*(11/12), 821-841.



- Riessman, C. K. (2002). Positioning gender identity in narratives of infertility: South Indian women's lives in context. In M. C. Inhorn, & F. Van Balen (Eds.), *Infertility around the* globe: New thinking on childlessness, gender and reproductive technologies: A view from the social sciences (pp. 152-170). Berkeley, CA: University of California Press.
- Robert, D., & Nachtigall, M. D. (2006). International disparities in access to infertility services. *Fertility and Sterility*, *85*, 871–875. doi: 10.1016/j.fertnstert.2005.08.066
- Rokicki, T. (2014). Towards God's number for Rubik's cube in the quarter-turn metric. *The College Mathematics Journal*, *45*(4), 242-253.
- Ronson, M., Lindsey, H., & Germanotta, S. J. A. (2016). Million Reasons. On *Joanne*[CD]. Malibu, California: Sony.
- Rosenthal, M. S. (2002). *The fertility sourcebook* (3rd ed.). New York, NY: McGraw-Hill Professional. Retrieved from http://books.google.co.za.
- Rothman, D., Kaplan, A. H., & Nettles, E. (1962). Psychosomatic infertility. American Journal of Obstetric Gynecology, 83, 373-381.
- Roudsari, R. L., & Allan, H. T. (2011). Women's experiences and preferences in relation to infertility counselling: A multifaith dialogue. *International Journal of Fertility & Sterility*, 5(3), 158-167.
- Roudsari, R. L., Allan, H. T., & Smith, P. A. (2007). Looking at infertility through the lens of religion and spirituality: A review of the literature. *Human Fertility*, 10(3), 141-149.
- Roudsari, R. L., Khadivzadeh, T., & Bahram, M. (2013). A grounded theory approach to understand the process of decision making on fertility control methods in urban society of Mashhad, Iran. *Iranian Journal of Nursing Midwifery Research*, 18(5), 408-415.
- Rubenstein, B. B. (1951). An emotional factor in infertility: A psychosomatic approach. *Fertility and Sterility*, *2*, 80-86.
- Rubik, E. (1983). U.S. Patent No. 4,378,116. Washington, DC: U.S. Patent and Trademark Office.
- Rubik's Cube [Online image]. (n.d.). Retrieved February 27, 2017 from https://en.wikipedia.org.
- Rutstein, S. O., & Shah, I. H. (2004, September). Infecundity, infertility, and childlessness in developing countries (DHS Report No. 9). Retrieved from http://www.who.int.
- Salhan, S. (2011). *Textbook of gynaecology*. New Delhi, India: Jaypee Brothers Medical Publishers.



- Sandelowski, M., & De Lacey, S. (2002). The uses of a "disease": Infertility as rhetorical vehicle. In: M. C. Inhorn & F. Van Balen (Eds.), *Infertility around the globe: New thinking on childlessness, gender, and reproductive technologies: A view from the social sciences* (pp.33-51). Los Angeles, CA: University of California Press.
- Saridi, M., & Georgiadi, E. (2010). Causes of infertility. *To Vima Tou Asklipiou*, *9*, 409-419. Retrieved from http://www.doaj.org.
- Savitz-Smith, J. (2003). Couples undergoing infertility treatment: Implications for counsellors. *Family Journal*, 11(4), 383-387.
- Schenker, J. G. (1992). Religious views regarding treatment of infertility by assisted reproductive technologies. *Journal of Assisted Reproduction and Genetics*, 9(1), 3-8. doi: 10.1007/BF01204106.
- Schenker, J. G. (1997). Infertility evaluation and treatment according to Jewish law. European Journal of Obstetrics & Gynecology and Reproductive Biology, 71(2), 113-121.
- Schlumpf, H. (n.d.). Inconceivable: The spiritual test of infertility. Retrieved from http://www.uscatholic.org.
- Schmidt, L. (2009). Social and psychological consequences of infertility and assisted Reproduction - What are the research priorities? *Human Fertility*, *12*(1), 14-20.
- Schmidt, L., Holstein, B. E., Boivin, J., Sångren, H., Tjørnhøj-Thomsen, T., Blaabjerg, J.,
 Rasmussen, P. E. (2003). Patients' attitudes to medical and psychosocial aspects of care in fertility clinics: Findings from the Copenhagen Multi-centre Psychosocial Infertility (COMPI) Research Programme. *Human Reproduction*, *18*(3), 628-637.
- Schneider, M. G., & Forthofer, M. S. (2005). Associations of psychosocial factors with the stress of infertility treatment. *Health & Social Work*, *30*(3), 183-191.
- Schrodinger, E. (1992). *What is life?: With mind and matter and autobiographical sketches*. UK: Cambridge University Press.
- Sejbaek, C. S., Hageman, I., Pinborg, A., Hougaard, C. O., & Schmidt, L. (2013). Incidence of depression and influence of depression on the number of treatment cycles and births in national cohort of 42 880 women treated with ART. *Human Reproduction*, 28, 1100-1109. doi: 10.1093/humanrep/des442.
- Serour, G. I. (2000). Ethical considerations of assisted reproductive technologies: A Middle Eastern perspective. *Middle East Fertility Society Journal*, *5*, 13-18.



- Serour, G. I. (2002). Attitudes and cultural perspectives on infertility and its alleviation in the Middle East area. In E. Vayena, P. J. Rowe, & P. D. Griffin (Eds.), *Current practices* and controversies in assisted reproduction: Report of a meeting on "Medical, Ethical and Social Aspects of Assisted Reproduction". Paper presented at WHO Headquarters in Geneva, Switzerland.
- Serour, G. I. (2005). OPINION Religious perspectives of ethical issues in ART 1. Islamic perspectives of ethical issues in ART. *Middle East Fertility Society Journal*, 10(3), 185-190.
- Serour, G. I. (2008). Medical and socio-cultural aspects of infertility in the Middle East. *ESHRE Monographs*, 2008(1), 34-41. doi: 10.1093/humrep/den143.
- Serour, G. I., Aboulghar, M. A., & Mansour, R. T. (1995). Bioethics in medically assisted conception in the Muslim world. *Journal of Assisted Reproduction and Genetics*, 12(9), 559 - 565.
- Sewpaul, V. (1999). Culture religion and infertility: A South African perspective. *British Journal of Social Work*, 29(5), 741-754.
- Sexton, M. B., Byrd, M. R., & Von Kluge, S. (2010). Measuring resilience in women experiencing infertility using the CD-RISC: Examining infertility-related stress, general distress, and coping styles. *Journal of Psychiatric Research*, 44(4), 236-241.
- Shah, I. H., & Ahman, E. (2009). Unsafe abortion: Global and regional incidence, trends, consequences and challenges. *Journal of Obstetrics and Gynaecology Canada*, 12, 1149–1158. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/20085681.
- Sharma, S., Mittal, S., & Aggarwal, P. (2009). Management of infertility in low resource countries. *BJOG: An International Journal of Obstetrics & Gynaecology*, *116*(1), 77-83. doi: 10.1111/j.1471-0528.2009.02311.x
- Shaw, R. L. (2011). Women's experiential journey toward voluntary childlessness: An interpretative phenomenological analysis. *Journal of Community & Applied SocialPsychology*, 21(2), 151-163.
- Sher Institute [Online image]. Retrieved October 10, 2015 from https://www.facebook.com.
- Shreffler, K. M., Greil, A. L., & McQuillan, J. (2011). Pregnancy loss and distress among US women. *Family Relations*, 60(3), 342-355.
- Singer, D., & Hunter, M. (2003). Assisted human reproduction: Psychological and ethical dilemmas. London, England: Whurr Publishers.



- Slade, P., O'Neil, C. O., Simpson, A. J., & Lashen, H. (2007). The relationship between perceived stigma, disclosure patterns, support and distress in new attendees at an infertility clinic. *Human Reproduction*, 22(8), 2309-2317.
- Smith, J. A. (1991). Conceiving selves: A case study of changing identities during the transition to motherhood. *Journal of Language and Social Psychology*, 10, 225-243. doi: 10.1177/0261927X91104001.
- Smith, J. A. (2004). Reflecting on the development of interpretive phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, 1, 39-54.
- Smith, J. A. (2008). *Qualitative psychology: A practical guide to research methods* (2nd ed.). London, England: Sage.
- Smith, J. A. (2010). Evaluating the contribution of interpretive phenomenological analysis. *Health Psychology Review*, *5*, 9-27. doi:10.1080/17437199.2010.510659.
- Smith, J. A., & Osborn, M. (2003). *Interpretive phenomenological analysis: Qualitative psychology*. London, England: Sage.
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretive phenomenological analysis: Theory, method and research*. London, England: Sage.
- Smith, J. A., Harre, R., & Van Langenhove, L. (1995). *Rethinking methods in psychology*. London, England: Sage.
- Souter, V. L., Penney, G., Hopton, J. L., & Templeton, A. A. (1998). Patient satisfaction with the management of infertility, *Human Reproduction*, *13*(7), 1831-1836.
- Speck, P. (2004). Spiritual concerns. In P. Edmonds, N. Sykes, & J. Wile (Eds.), *Management* of advanced disease (pp. 471-481). London, England: Arnold.
- Stanton, A. L., & Dunkel-Schetter, C. (1991a). Psychological adjustment to infertility. In A.
 L. Stanton & C. Dunkel-Schetter (Eds.), *Infertility: Perspectives from stress and coping research* (pp. 3-16). New York, NY: Plenum Press.
- Stanton, A. L., & Dunkel-Schetter, C. (1991b). Cognitive appraisals, coping processes, and adjustment to infertility. In A. L. Stanton & C. Dunkel-Schetter (Eds.), *Infertility: Perspectives from stress and coping research* (pp. 87-108). New York, NY: Plenum Press.
- Stephen, E. H. & Chandra, A. (2000). Use of infertility services in the United States: 1995. *Family Planning Perspectives*, 32(3), 132-137.



- Steuber, K. R., & Solomon, D. H. (2008). Relational uncertainty, partner interference, and infertility: A qualitative study of discourse within online forums. *Journal of Social & Personal Relationships*, 25(5), 831-855.
- Stewart, M., Brown, J. B., Weston, W. W., McWhinney, I. R., McWilliam, C. L., & Freeman,
 T. R. (1999). *Patient-centered medicine: Transforming the clinical method*. Thousand
 Oaks, California: Sage Publication.
- Sturrock, D. (2011). *Storyteller The life of Roald Dahl*. United Kingdom: William Collins Publishing.
- Su, T. J., & Chen, Y. C. (2006). Transforming hope: The lived experience of infertile women who terminated treatment after in vitro fertilization failure. *Journal of Nursing*, 14(1), 46-53.
- Sultana, A., Rahman, K. U., & Nagaraj, R. B. (2011). Conception in unilateral right tubal blockage with herbomineral formulations: A case report. *Journal of Alternative and Complementary Medicine*, 17(6), 557-561. doi: 10.1089/acm.2010.0202.
- Sundby, J. (1997). Infertility in the Gambia: Traditional and modern healthcare. *Patient Education and Counseling*, *31*(1), 29-37.
- Sundby, J. (2002). Infertility and healthcare in countries with less resources. In M. C. Inhorn & F. Van Balen. (Eds.), *Infertility around the globe: New thinking on childlessness, gender and reproductive technologies: A view from the social sciences* (pp. 247-259). Berkeley, CA: University of California Press.
- Sundby, J., & Jacobus, A. (2001). Health and traditional care for infertility in the Gambia and Zimbabwe. In J. T. Boerma & Z. Mgalla (Eds.), *Women and infertility in sub-Saharan Africa: A multidisciplinary perspective* (pp.257-268). Amsterdam: Royal Tropical Institute.
- Sundby, J., Mboge, R., & Sonko, S. (1998). Infertility in Gambia: Frequency and healthcare seeking. *Social Science and Medicine*, 46(7), 891-899.
- Sundby, J., Schmidt, L., Heldaas, K., Bugge, S., & Tanbo, T. (2007). Consequences of IVF among women: 10 years post-treatment. *Journal of Psychosomatic Obstetrics & Gynecology*, 28(2), 115-120.
- Swinton, J., Garnett, G. P., Brunham, R. C., & Anderson, R. M. (1992). Gonococcal infection, infertility, and population growth: I. Endemic states in behaviourally homogeneous growing populations. *IMA Journal of Mathematics Applied in Medicine & Biology*, 9, 107-126. doi: 10.1093/imammb/9.2.107.



- Tain, L. (2003). Health inequality and users' risk-taking: A longitudinal analysis in a French reproductive technology centre. *Social science & medicine*, *57*(11), 2115-2125.
- Tangwa, G. B. (2002). ART and African sociocultural practices: Worldview, belief and value systems with particular reference to francophone Africa. In E. Vayena, P. J. Rowe, & P. D. Griffin (Eds.), *Current practices and controversies in assisted reproduction* (pp. 55-59). Geneva, Switzerland: World Health Organization [WHO].
- Taylor, C. (1985). Self-interpreting animals. In C. Taylor (Ed.), *Philosophical papers 1: Human agency and language* (pp. 45-47). Cambridge, England: Cambridge University Press.
- Taymor, M. L., & Bresnick, E. (1979). Emotional stress and infertility. *Infertility*, 2(1), 39-47.
- Teede, H., Deeks, A., & Moran, L. (2010). Polycystic ovary syndrome: A complex condition with psychological, reproductive and metabolic manifestations that impact on health across the lifespan. *BMC Medicine*, 8(1), 126 – 136. doi: 10.1186/1741-7015-8-41.
- Teoh, P. J., & Maheshwari, A. (2014). Low-cost in vitro fertilization: Current insights. International Journal of Women's Health, 6, 817-827. doi: 10.2147/IJWH. S51288.
- Terre Blanche, M., & Durrheim, K. (2002). *Research in practice: Applied method for the social sciences*. Cape Town, South Africa: University of Cape Town Press.
- Throsby, K., & Gill, R. (2004). "It's different for men": Masculinity and IVF. *Men & Masculinities*, *6*(4), 330-348.
- Ticinelli, I. (2012). The psychosocial impact of infertility on African American women: Agrounded theory study (Doctoral dissertation). Retrieved from ProQuest Dissertations and Theses Database. (UMI No. 3518884).
- Touroni, E., & Coyle, A. (2002). Decision-making in planned lesbian parenting: Aninterpretive phenomenological analysis. *Journal of Community & Applied SocialPsychology*, 12(3), 194-209. doi: 10.1002/casp.672.
- Tudge, J. R. H., Mokrova, I., Hatfield, B. E., & Karnik, R. B. (2009). Uses and misuses of Bronfenbrenner's bioecological theory of human development. *Journal of Family Theory & Review*, 1, 198-210.
- Turner, A., Barlow, J., & Ilbery, B. (2002). Play hurt, live hurt: Living with and managing osteoarthritis from the perspective of ex-professional footballers. *Journal of Health Psychology*, 7(3), 285-301.



- Turpin, G., Barley, V., Beail, N., Scaife, J., Slade, P., Smith, J. A., & Walsh, S. (1997).
 Standards for research projects and theses involving qualitative methods: suggested guidelines for trainees and courses. *Clinical Psychology Forum*, 108, 3-7.
- Ulrich, M., & Weatherall, A. (2000). Motherhood and infertility: Viewing motherhood through the lens of infertility. *Feminism & Psychology*, *10*(3), 323-326.
- Unruh, A. M., & McGrath, P. J. (1985). The psychology of female infertility: Toward a new perspective. *Health Care for Women International*, *6*(5-6), 369-381.
- Valkenburg, P. M., & Peter, J. (2009). Social consequences of the internet for adolescents: A decade of research. *Current Directions in Psychological Science*, 18(1), 1-5.
- Van Balen, F. (2002). The psychologization of infertility. In M. C. Inhorn & F. Van Balen (Eds.), *Infertility around the globe: New thinking on childlessness, gender, and reproductive technologies: A view from the social sciences* (pp. 79-98). Los Angeles, CA: University of California Press.
- Van Balen, F., & Gerrits, T. (2001). Quality of infertility care in poor-resource areas and the introduction of new reproductive technologies. *Human Reproduction*, *16*(2), 215-219.
- Van Balen, F., & Inhorn, M. C. (2002). Interpreting infertility: A view from the social sciences. In M. C. Inhorn & F. Van Balen (Eds.), *Infertility around the globe: New thinking on childlessness, gender, and reproductive technologies: A view from the social sciences* (pp. 3 32). Los Angeles, CA: University of California Press.
- Van Bavel, J. (2013). The world population explosion: Causes, backgrounds and projections for the future. *Facts, Views & Vision in ObGyn*, *5*, 281-291.
- Van Breda, R. A. (1989). Aspects of subjective experience of married couples during an infertility treatment programme (Doctorial dissertation). University of Orange Free State, South Africa.
- Van der Spuy, Z. M. (2009). HIV and reproductive health: A South African experience. *Reproductive BioMedicine Online*, 18, 3-10.
- Verhaak, C. M., Smeenk, J. M. J., Evers, A. W. M., Kremer, J. A. M., Kraaimaat, F. W., & Braat, D. D. M. (2007). Women's emotional adjustment to IVF: A systematic review of 25 years of research. *Human Reproduction Update*, 13(1), 27-36.
- Wahrman, M. Z. (2016). Assisted reproduction and Judaism. *Jewish Virtual Library*. Retrieved from http://www.jewishvirtuallibrary.org.
- Walther, S., & Fox, H. (2012). Narrative therapy and outsider witness practice: Teachers as a community of acknowledgement. *Educational & Child Psychology*, *29*(2), 8-17.



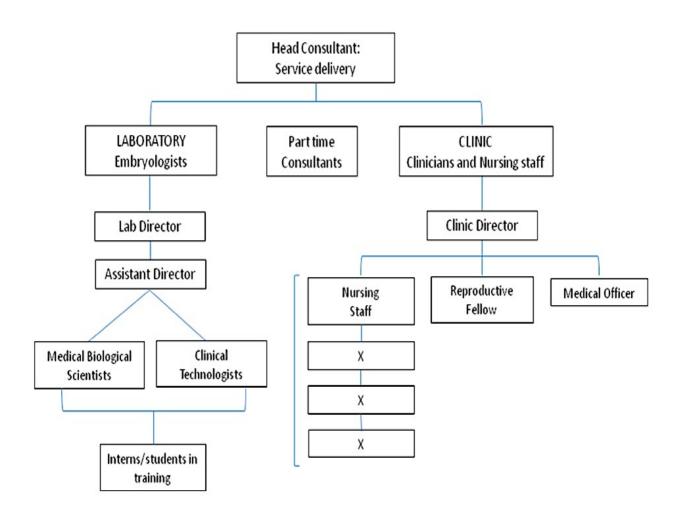
- Watkins, D., & Jefferson, S. O. (2013). Recommendations for the use of online social support for African American men. *Psychological Services*, *10*(3), 323-332.
- Webb, R. E., & Daniluk, J. C. (1999). The end of the line: Infertile men's experiences of being unable to produce a child. *Men & Masculinities*, 2(1), 6-25.
- White, K. I., Williams, T. F., & Greenberg, B. G. (1996). The ecology of medical care. *Bulletin New York Academy of Medicine*, 73, 187-205.
- White, L., & McQuillan, J. (2006). No longer intending: The relationship between relinquished fertility intentions and distress. *Journal of Marriage & Family*, 68(2), 478-490.
- White, L., McQuillan, J., & Greil, A. L. (2006). Explaining disparities in treatment seeking: The case of infertility. *Fertility & Sterility*, 85(4), 853-857.
- Whiteford, L. M., & Gonzalez, L. (1995). Stigma: The hidden burden of infertility. Social Science & Medicine, 40(1), 27-36.
- Whitley, B. E. (2002). *Principles of research in behavioral science* (2nd ed.). New York, NY: McGraw-Hill.
- 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.
- Wischmann T., Stammer, H., Scherg, H., Gerhard, I., & Verres, R. (2001). Psychosocial characteristics of infertile couples: A study by the "Heidelberg Fertility Consultation Service". *Human Reproduction*, 16(8), 1753–1761.
- Wischmann, T. H. (2003). Psychogenic infertility: Myths and facts. *Journal of Assisted Reproductive Genetics*, 20(12), 485-494.
- World Cube Association (2016). *European Rubik's Cube Championship*. Retrieved from https://www.worldcubeassociation.org.
- World Health Organization [WHO]. (2015). Sexual and reproductive health: Infertility definitions and terminology. Retrieved from http://www.who.int.
- World Health Organization and World Bank. (2011). *World report on disability*. Retrieved from http://www.who.int/disabilities/world_report/2011/report.pdf.
- Yadley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health*, 15, 215 228.
- Yang, Y. S., Hwang, J. L., Ho, H. N., Lien, Y. R., Lin, H. R., Chiu, Y. H., & Lee, T. Y. (1991). Translaparoscopic tubal embryo transfer: Preliminary experience at National Taiwan University Hospital. *Asia-Oceania Journal of Obstetrics & Gynaecology*, 17(3), 255-259.



- Yebei, V. N. (2000). Unmet needs, beliefs and treatment-seeking for infertility among migrant Ghanaian women in the Netherlands. *Reproductive Health Matters*, 8(16), 134-141.
- Zahavi, D. (2008). *Subjectivity and selfhood: Investigating the first-person perspective*. London, England: The MIT Press.
- Zegers-Hochschild, F., Admson, G. D., De Mouzon, J. Ishihara, O., Mansour, R., Nygren, K., Van der Poel, S. (2009). The International Committee for Monitoring Assisted Reproductive Technology (ICMART) and the World Health Organization (WHO) revised glossary on ART Terminology, 2009. *Human Reproduction*, 24, 2683-2687. doi: 10.1093/humrep/dep343.
- Zucker, A. N. (1999). The psychological impact of reproductive difficulties on women's lives. *Sex Roles*, *40*(9), 767-786.



Appendix A: Staff Structure of REU





Appendix B: Research Permission and Ethical Approval



UNIVERSITEIT VAN PRETORIA UNIVERSITY OF PRETORIA YUNIBESITHI YA PRETORIA

Faculty of Health Sciences Department of Obstetrics and Gynaecology Reproductive and Endocrine Unit Steve Biko Academic Hospital

6th June 2012

To: Ethics Committee Faculty of Humanities

acany or mananine

University of Pretoria

Re: PhD (Psychology) – "Involuntary childlessness: An interpretive phenomenological inquiry into couples' experiences of infertility treatment in the South African public health sector."

Ms. Adele Wybourn (student number: 26387507) would like to perform her research for the completion of her PhD in Psychology, at the Reproductive and Endocrine Unit, Department of Obstetrics & Gynaecology, Steve Biko Academic Hospital.

This letter confirms that Ms. Wybourn, together with her supervisor Prof. Lourens Human, discussed the details with Prof. Carin Huyser (co-supervisor) and Dr. Krushmee Singh, and full support is given in her endeavour.

We trust that all is in order.

Kind regards,

Prof. Carin Huyser

(See)

RBL: Dep Director Medical Biological Sciences

Dr. Krushmee Singh Clinic: Medical Officer

Prof. BG. Lindeque Head: Department Obstetrics and Gynaccology

Steve Biko Academic Hospital : Rm 72352 University of Pretoria PRETORIA 0002 Republic of South Africa Tel: +27 12 354 2067/2208 Fax: +27 12 329 6258r Carin.huyser@up.ac.za

wew.up.ac.za





UNIVERSITEIT VAN PRETORIA UNIVERSITY OF PRETORIA YUNIBESITHI YA PRETORIA

> Faculty of Humanities Research Ethics Committee

10 April 2013

Dear Prof Maree

Project:Involuntary childlessness: an interpretative
phenomenological inquiry into couples' experiences of
infertility treatment in the South African public health sectorResearcher:A WybournSupervisor:Prof L HumanDepartment:PsychologyReference number:26387507

Thank you for your response to the Committee's correspondence of 5 March 2013.

I have pleasure in informing you that the Research Ethics Committee formally **approved** the above study at an *ad hoc* meeting held on 9 April 2013. Data collection may however, only commence once written proof of permission has been obtained from the Faculty of Health Science and the hospital.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should your actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

nhli

Prof. Sakhela Buhlungu Chair: Research Ethics Committee Faculty of Humanities UNIVERSITY OF PRETORIA e-mail: sakhela.buhlungu@up.ac.za

Research Ethics Committee Members: Dr L Blokland; Prof S Buhlungu (Chair); Prof M-H Coetzee; Dr JEH Grobler; Prof KL Harris; Ms H Klopp Prof A Miambo, Dr C Panebianco-Warrens; Prof GM Spies; Prof E Taljard; Dr FG Wolmarans, Dr P Wood



Appendix C: Invitation Letter to Participants



Faculty of Health Sciences Department of Obstetrics and Gynaecology

..... 2013

RESEARCH INVITATION

Dear Patient,

My name is Adele Wybourn. I am a Counselling Psychologist, registered for my PhD (Psychology) degree at the University of Pretoria. The topic of my research project is: "Involuntary childlessness: An interpretive phenomenological inquiry into couples' experiences of infertility treatment in the South African public health sector."

I would hereby like to invite you to consider participating in this research project, as the purpose of this research project is to understand couples' experiences of infertility treatment within the South African public health sector. Based on this research working guidelines will be proposed for health professionals working with couples undergoing infertility treatment within the South African public health sector.

If you are interested in participating in this research project, you please need to sign the "Research Contact" section of this letter, as this will grant me permission to convey more detailed information to you regarding the research project. Once I have given you more detailed information regarding the research project, you can finally decide if you are willing to participate voluntarily in this research project. I also want to assure you that anonymity and confidentiality will be upheld during the entire research process.



Prof. Lourens Human, from the Department of Psychology at the University of Pretoria, as well as Prof. Carin Huyser, from the Department of Obstetrics and Gynaecology at the University of Pretoria, will be my research supervisors.

Kind regards,

Mrs. Adele Wybourn Researcher Cell no.: 082 561 9888 E-mail: wybourn@gmail.com



RESEARCH CONTACT

Partner 1

I hereby acknowledge that I am interested in participating in the PhD (Psychology) research project of Mrs. Adele Wybourn titled: "Involuntary childlessness: An interpretive phenomenological inquiry into couples' experiences of infertility treatment in the South African public health sector." I hereby grant Mrs. Adele Wybourn permission to convey more detailed information to me regarding the research project, with the purpose of making an informed decision regarding my participation in this research project.

Name & Surname (Partner 1)	Signature	Date

Partner 2

I hereby acknowledge that I am interested in participating in the PhD (Psychology) research project of Mrs. Adele Wybourn titled: "Involuntary childlessness: An interpretive phenomenological inquiry into couples' experiences of infertility treatment in the South African public health sector." I hereby grant Mrs. Adele Wybourn permission to convey more detailed information to me regarding the research project, with the purpose of making an informed decision regarding my participation in this research project.

Name & Surname (Partner 2)	Signature	Date



Appendix D: Research Information Letter and Consent



VAN PRETORIA

Faculty of Humanities Department of Psychology & Faculty of Health Sciences

Department of Obstetrics and Gynaecology

RESEARCH INFORMATION

Dear Participant,

The following information is important regarding this research project. Once you have read the information and are willing to participate in the project please complete the research consent form.

- **Researcher:** I am a Counselling Psychologist, registered for my PhD (Psychology) degree at the University of Pretoria). This research project will fulfil the requirements of the abovementioned degree. Prof. Lourens Human from the Department of Psychology at the University of Pretoria, as well as Prof. Carin Huyser from the Department of Obstetrics and Gynaecology at the University of Pretoria, will act as research supervisors for this research project.
- Title: The title of the study is: "Involuntary childlessness: An interpretive phenomenological inquiry into couples' experiences of infertility treatment in the South African public health sector."
- **Purpose:** The focus of this research project is to explore couples' experiences of infertility treatment in the South African public health sector, with the purpose of establishing working guidelines for health professionals involved in infertility treatment within the South African public health sector.



Procedures: This research project is qualitative in nature and will require you to participate in the following activities:

- 1) Attend one 90-minute semi-structured interview with the aim of gaining background knowledge of you as a couple.
- 2) Attend a maximum of three 120 minute semi-structured interviews with the view of exploring your experience of infertility treatment as a couple. These interviews will take place after each infertility treatment cycle. If you do fall pregnant before the third infertility treatment cycle, you will not be expected to participate in any semistructured interviews after conception.

All interviews will be recorded by means of a digital Dictaphone to accurately transcribe your experiences. I will transcribe all interviews. I shall make all transcriptions available to you should you wish to read them. Every attempt will be made to provide an accurate reflection of your experience in this research project and your identities will remain anonymous both in the transcriptions and in the PhD dissertation. Interviews will be scheduled concurrently with your treatment cycles. The interviews will be conducted at the Reproductive and Endocrine Unit at the Steve Biko Academic Hospital.

- **Risks:** There are no perceived physical or psychological risks for your participation. However, should you as a couple and/or individual in your personal capacity feel overwhelmed by the interviews, counselling will be provided to you on a pro-bono basis by a Counselling Psychologist, Leatia Stemmet.
- Benefits:There are no financial gains by participating in the research project.However, you may benefit by exploring your experiences about the
infertility treatment you are both receiving.
- **Rights:** Participation in this research project is completely voluntary. You may withdraw from participating at any time and without negative consequences for doing so. Your right to receiving infertility treatment is not dependent on participating in this project. Therefore, you may at any point withdraw without this impacting the medical treatment you are receiving.



- **Confidentiality:** All information will be treated as confidential. Anonymity will be assured and the material will be destroyed if you wish to withdraw from the research project.
- Material:After completion of the research project the transcribed material will be
stored for archival purposes in the Department of Psychology at
University of Pretoria for 15 years.
- Publication:The findings of this study will be published in a PhD dissertation, as well
as a peer-reviewed academic journal.
- **Researcher:** If any clarity or more detail is required feel free to contact me on:

Name: Adele Wybourn Cell no.: 082 561 9888 E-mail:wybourn@gmail.com

.....

Mrs. Adele Wybourn Researcher

.....

Prof. C. Huyser Co-Supervisor: Department of Obstetrics and andGynaecology Faculty of Health Sciences

Prof. B.G. Lindeque Head: Department of Obstetrics Gynaecology Faculty of Health Sciences

Prof. L.H. Human Supervisor: Department of Psychology Faculty of Humanities

Prof. D. Maree Head: Department of Psychology Faculty of Humanities



RESEARCH CONSENT

Partner 1

I, (Partner 1) (Full Name and Surname) hereby acknowledge that I have read and understand this research information. I acknowledge that any questions I may have had I have had the opportunity to discuss them with the researcher and she has discussed and answered all of the concerns. I hereby agree to participate in the research project. I accept and agree with the conditions as stated above.

Name & Surname (Partner 1)	Signature	Date

Partner 2

I, (Partner 2) (Full Name and Surname) hereby acknowledge that I have read and understand this research information. I acknowledge that any questions I may have had I have had the opportunity to discuss them with the researcher and she has discussed and answered all of the concerns. I hereby agree to participate in the research project. I accept and agree with the conditions as stated above.

Name & Surname (Partner 2)	Signature	Date



INFORMATION LEAFLET AND INFORMED CONSENT FOR NON-CLINICAL RESEARCH

(e.g. educational, health systems or nonclinical operational research)

Dear Participant,

TITLE OF STUDY:

"Involuntary childlessness: An interpretive phenomenological inquiry into couples' experiences of infertility treatment in the South African public health sector."

1) INTRODUCTION

I would like to invite you to participate in a research study. This information leaflet will help you to decide if you want to participate. Before you agree to take part, youshould fully understand what is involved. If you have any questions that thisleaflet does not fully explain, please do not hesitate to ask the investigator Adele Wybourn.

2) THE NATURE AND PURPOSE OF THIS STUDY

This research project would like to explore couple's experiences of infertility treatment in the South African public health sector, with the purpose of establishing working guidelines for health professionals involved in infertility treatment in the public health sector. You and your partner are a very important source of information on trying to explore experiences of infertility treatment as a couple.

3) EXPLANATION OF PROCEDURES TO BE FOLLOWED

This study involves will require you to participate in the following activities:

Attend one 90-minute semi-structured interview with the aim of gaining background knowledge of you as a couple. During your course of infertility treatment, I would then ask if you could both attend a maximum of three 120 minute semi-structured interviews with the view of exploring your experience of infertility treatment as a couple. These interviews will take place after each infertility treatment cycle. If you do fall pregnant before the third infertility treatment cycle, you will not be expected to participate in any semi-structured interviews after conception.

4) RISK AND DISCOMFORT INVOLVED

There are no perceived physical or psychological risks for your participation. However, should you as a couple and/or individual in your personal capacity feelOverwhelmed by the interviews, counselling will be provided to you on a pro-bono basisby a Counselling Psychologist, Leatia Stemmet.



5) POSSIBLE BENEFITS OF THIS STUDY

There are no financial gains by participating in the research project. However, you maybenefit by exploring your experiences about the infertility treatment you are bothreceiving.

6) WHAT ARE YOUR RIGHTS AS A PARTICIPANT?

Participation in this research project is completely voluntary. You may withdraw fromparticipating at any time and without negative consequences for doing so. Your right to receiving infertility treatment is not dependent on participating in this project. Therefore, you may at any point withdraw without this impacting the medical treatment you are receiving.

7) HAS THE STUDY RECEIVED ETHICAL APPROVAL?

This study has received written approval from the Research Ethics Committeeof the Faculty of Health Sciences at the University of Pretoria and The Faculty of Humanities at the University of Pretoria. Copies of the approval letters are available if you wish to have one.

8) INFORMATION AND CONTACT PERSON

The contact person for the study is Adele Wybourn.If you haveany questions about the study please contact me on 082 561 9888.Alternatively, you may e-mail me: wybourn@gmail.com.

9) COMPENSATION

Your participation is voluntary. No compensation will be given for your participation.

10) CONFIDENTIALITY

All information that you give will be kept strictly confidential. Once I haveanalysed the information no one will be able to identify you. Research reports and articles in scientific journals will not include any information that mayidentify you.

CONSENT TO PARTICIPATE IN THIS STUDY

I confirm that the person asking my consent to take part in this study has told me aboutnature, process, risks, discomforts and benefits of the study. I have also received, readand understood the above written information (Information Leaflet and InformedConsent) regarding the study. I am aware that the results of the study, includingpersonal details, will be anonymously processed into research reports. I amparticipating willingly. I have had time to ask questions and have no objection toparticipate in the study. I understand that there is no penalty should I wish todiscontinue with the study and my withdrawal will not affect any treatment or access totreatment in any way.



I have received a signed copy of this informed consent agreement.

Participant's name:	(Please print	
Participant's signature:		Date:
Investigator's name:	(Please print	
Investigator's signature:		Date:
Witness's Name:	(Please print	
Witness's signature:		Date:

VERBAL INFORMED CONSENT

I, the undersigned, have read and have fully explained the participant informationleaflet, which explains the nature, process, risks, discomforts and benefits of thestudy to the participant whom I have asked to participate in the study. The participant indicates that s/he understands that the results of the study, includingpersonal details regarding the interview will be anonymously processed into aresearch report. The participant indicates that s/he has had time to ask questions andhas no objection to participate in the interview. S/he understands that there is nopenalty should s/he wish to discontinue with the study and his/her withdrawal will notaffect any treatment or access to treatment in any way.



I hereby certify that the client has agreed to participate in this study.

Participant's name:		
	(Please prin	<i>t</i>)
Person seeking consent:		
	(Please print)	
Signature:		Date:
Witness's Name:		а
	(Please prin	t)
Witness's signature:		Date:



Appendix E: Interview Schedule

CONTEXT INTERVIEW

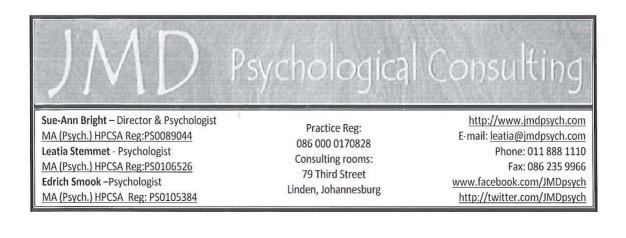
- 1. Can you each tell me where you come from?
- 2. How did the two of you meet?
- If in a co-habit relationship:
 How long have you been in a co-habit relationship?
 Can you describe your experience of your co-habit relationship?
- 4. If in a marital relationship: How long have you been married? Can you describe your experience of your marital relationship?
- 5. When did you decide to start trying to have children?
- 6. When did you know there might be a problem in conceiving?
- 7. After you suspected there was a problem in conceiving, where did you first go for help?
- 8. How does your culture view childlessness?
- 9. What has the doctor at Steve Biko told you about your treatment options and do you understand what this entails?
- 10. Do you have any questions you would like to ask me regarding what we have been talking about today?
- 11. Is there anything else you would like to share with me today?

RESEARCH INTERVIEWS (Interviews 2-4)

- 1. Can you please describe your experiences before the infertility treatment cycle?
- 2. Can you please describe your experience during the infertility treatment cycle?
- 3. Can you please describe your experiences after the infertility treatment cycle?



Appendix F: Support Services



1 March 2012

TO WHOM IT MAY CONCERN

I, Leatia Stemmet, am a registered Counselling Psychologist with the Health Professions Council of South Africa (HPCSA).

I am willing to assist those participating in Adele Wybourn's research on: "Involuntary childlessness: An interpretive phenomenological inquiry into couples experiences of infertility treatment in the South African public health sector", with counselling free of charge should they wish to be assisted.

Kind regards,

Stemmet

LeatiaStemmet

Counselling Psychologist JMD Psychological Consulting 011 888-1110 <u>leatia@jmdpsych.com</u> <u>www.jmdpsych.com</u>