

**Diagnosing 'his' infertility:  
Men's experiences and reflections on the diagnosis of  
azoospermia**

by

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## **Declaration**

I confirm that the work submitted is my own and that appropriate credit has been given where reference was made to the work of others.

Stamatios Karavolos  
24th March 2016

## Abstract

**Background:** A male cause is the main or a contributing factor in up to 50% of couples presenting with infertility. Azoospermia (lack of sperm in the semen) is present in approximately 15% of infertile men. Unlike psychosocial aspects of female infertility, male attitudes to their own infertility are poorly understood. Male infertility can potentially have a significant impact on psychological and social aspects of men's lives, impacting negatively on self-image, relationships and causing psychological distress. Objective data in this area is lacking.

**Aim:** The aim of this study was to assess the impact of the diagnosis of azoospermia on men's psychological and social functioning.

**Method:** This was a qualitative interview study, involving fifteen men with azoospermia attending a fertility clinic. All men were over twenty three years of age and suffering from primary infertility for more than a year. Participants gave their own account of how they perceived the experience of receiving the diagnosis, undergoing further investigations and having treatment. Data were collected between June 2013 and November 2013. The interviews were fully transcribed and analysed thematically using NVivo<sup>®</sup> software.

**Results:** Major themes that emerged from the interviews included 'reaction to the initial diagnosis', 'lack of cause and explanation', 'effect on interpersonal relationships', 'disclosure of the diagnosis', 'support seeking' and 'decisions regarding fertility treatment'. Key findings highlighted a feeling of shock and disbelief as a prominent part of men's experience. Many men said that they never expected to be told of a 'completely zero' sperm count. Finding out was described as 'heartbreaking', 'devastating', 'confusing' and 'sad'. The possibility of biological fatherhood was perceived as non-existent by some, with one commenting: 'It felt as it was the end of the world'. One third of participants felt the diagnosis to be a threat to their masculinity, and to have a negative impact on their sense of self-confidence. Men found the lack of a precise aetiology frustrating and distressing. Most men were reluctant to share the diagnosis beyond close family members. The diagnosis brought partners closer together in most cases. Most men did not feel the need to seek external psychological support following the diagnosis and were satisfied with the support provided by clinic staff and their partners. A sperm retrieval operation was in most cases the only hope for establishing biological fatherhood. Decision-

making with regards to this and donor sperm treatment took into account multiple factors, including the risk of potential complications and side effects, their partner's influence, and attitudes towards using donor sperm.

**Conclusion:** Male infertility impacts substantially on men's quality of life and healthcare professionals should be aware of this when investigating and treating patients with azoospermia. An improved understanding of men's experiences is important for the provision of optimal clinical and psychosocial care. Better education and publicity about male factor infertility will reduce stigma and encourage men to seek help sooner. Men find the lack of specific aetiology frustrating and therefore further research is required into the aetiology of male infertility.

## Dedication

*Dedicated to my parents Ilias and Eugenia, and my fiancé  
Nikoletta for their continuous support and inspiration*

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It has been a long and winding road to the final submission of this thesis. I would like to thank to the fifteen men and their partners who participated in this research study. Without their willingness and openness to share such intimate and sometimes painful details of their personal lives, this study would not have been possible.

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## Table of contents

Title		i
Declaration		ii
Abstract		iii
Dedication		v
Acknowledgements		vi
Table of contents		viii
List of tables		xv
List of figures		xvi
<b>Chapter 1</b>	<b>Introduction</b>	<b>1</b>
1.1	Definition of infertility	1
1.2	Magnitude of the problem and causes of infertility	2
1.3	The impact of infertility and its treatment on individuals	2
1.4	Gender differences in experiencing infertility	3
1.5	Why is there relative lack of research on men?	4
1.6	Purpose of this thesis	5
1.7	Summary	6
<b>Chapter 2</b>	<b>Literature review</b>	<b>7</b>
2.1	Introduction	7
2.1.1	Socio-cultural aspects of reproduction and infertility	7
2.1.1.1	Desire for parenthood	7
2.1.1.2	Gender, masculinity and infertility	12
2.1.1.2.1	Gender and masculinity	12

2.1.1.2.2	Masculinity and infertility	14
2.2	Men and help-seeking	15
2.3	The impact of infertility on men	18
2.3.1	Physical impact of infertility and infertility treatment	18
2.3.1.1	Undergoing investigation and treatment	18
2.3.1.2	Infertility and male sexual function	19
2.4	Psychosocial impact of infertility	21
2.4.1	Theories that explain the psychosocial impact of infertility	21
2.4.2	Infertility and psychological distress	25
2.4.3	The effect of infertility on relationships	26
2.4.3.1	Impact on the partnership	26
2.4.3.2	Impact on the relationship with family and friends	28
2.4.3.3	The sense of loss associated with infertility	28
2.5	Summary	29
<b>Chapter 3</b>	<b>Methodology</b>	<b>31</b>
3.1	Social science research	31
3.1.1	The aims of qualitative research	32
3.1.2	Qualitative research designs and data collection techniques	34
3.2	Project design	35
3.3	Research governance	36
3.3.1	Ethical approval and consent	36
3.3.2	Confidentiality and support	36
3.3.3	Research management	37
3.3.4	Funding	37

3.4	Sampling	37
3.5	Recruitment and participants	38
3.6	Interview arrangements	39
3.7	Data generation	39
3.7.1	Topic guide	40
3.8	Data analysis	41
3.9	Summary	41
<b>Chapter 4</b>	<b>Men's initial concerns, reaction to the given diagnosis and further investigation</b>	<b>43</b>
4.1	Introduction to findings	43
4.2	The interviews	45
4.3	Initial infertility concerns and reaction to the given diagnosis	45
4.3.1	Concerns leading to infertility investigation	46
4.3.1.1	Reasons for seeking help	46
4.3.1.2	Lack of awareness about male factor infertility	47
4.3.1.3	Initiation of fertility investigation	48
4.3.1.4	Reluctance to seek help	48
4.3.2	Reaction to the given infertility diagnosis	49
4.3.2.1	Disbelief and denial	49
4.3.2.2	Emotional response	50
4.3.3	Explanation of the diagnosis and referral to the fertility centre	55
4.3.3.1	Explanation of the diagnosis	55
4.3.3.2	Referral to the fertility centre for expert opinion	56

4.4	Referral to the fertility centre: expectations from the medical consultation	57
4.4.1	Visiting the fertility centre	58
4.4.2	Information provision prior to visiting the fertility centre	61
4.4.3	Feeling not alone	61
4.4.4	Producing a semen sample for analysis	62
4.4.4.1	General thoughts about the semen sample production	62
4.4.4.2	Production room facilities	64
4.4.4.3	Recommendations for facility improvements	66
4.4.5	Lack of specific cause for the azoospermia	67
4.4.5.1	Past experiences	79
4.4.6	Consultation without partner present	71
4.4.7	Communication and information seeking through online support groups and forums	72
4.4.7.1	The Internet as a means of social support	75
4.4.8	The experience of having a physical examination	75
4.4.8.1	Expectation with regards to the physical examination	75
4.4.8.2	Feeling nervous and embarrassed	77
4.4.9	General comments about the clinic and staff	78
4.5	Summary	78
<b>Chapter 5</b>	<b>Disclosure of the diagnosis, means of coping and impact on men and their relationships</b>	<b>81</b>
5.1	Disclosure of the diagnosis	81
5.1.1	Disclosure to family members	81
5.1.2	Telling close friends	83
5.1.3	Telling people at work	84
5.1.4	Reasons for non-disclosure of the diagnosis	86

5.2	Means of coping and support seeking	88
5.2.1	Having a supportive partner and family members	88
5.2.2	Staying active and keeping busy at work	90
5.2.3	Seeking help from a counsellor	90
5.2.4	Positive thinking as a means of coping	93
5.3	Perceived loss of masculinity	94
5.4	Impact on relationships	96
5.4.1	Situation brought partners closer together	96
5.4.2	Conflict and negative impact on the relationship	97
5.4.3	Feeling guilty and wanted to leave the relationship	98
5.4.4	Communication between partners	99
5.4.5	Effect on sexual the relationship	100
5.5	Effect on everyday life and work	101
5.6	Summary	101
<b>Chapter 6</b>	<b>Decisions about fertility treatment</b>	<b>103</b>
6.1	The sperm retrieval operation	103
6.1.1	General feelings and thoughts about the operation	103
6.1.2	Reasoning and decision making about the operation	104
6.1.3	Fear of potential complications and side effects	105
6.1.4	Partner's influence on decision to have an operation	106
6.2	Attitudes and feelings of participants towards using donor sperm	108
6.2.1	General considerations and issues about the use of	108

	donor sperm	
6.2.2	Other factor consideration in decision-making about using donor sperm	110
6.2.2.1	Nurture vs Nature and disclosure of donor identity	110
6.2.2.2	Donor anonymity	111
6.2.2.3	The importance of external appearance and resemblance to parent's personality traits	112
6.2.2.4	Fear of relationship breakdown	115
6.2.2.4.1	Men fearing that their partner will leave the relationship	115
6.2.2.4.2	Women fearing that their partner will leave the relationship	116
6.2.2.5	Female partner's thoughts on using donor sperm	117
6.2.2.6	External influences in decision-making about using donor sperm	119
6.3	Summary	121
<b>Chapter 7</b>	<b>Discussion of key findings and conclusions</b>	<b>123</b>
7.1	Interpretation of findings	123
7.1.1	The men and the interviews	123
7.1.2	Reflection on my role as a qualitative researcher	124
7.1.3	Seeking fertility investigations: consulting the GP	125
7.1.4	Are GPs unsympathetic to infertile men?	127
7.1.5	Male infertility awareness and reaction to the diagnosis	128
7.1.6	Visiting the specialist clinic	131
7.1.7	The search for a cause	133
7.1.8	Preferred sources of information and support	133
7.1.8.1	The internet	133

7.1.8.2	The clinic	134
7.1.8.3	Professional counselling	134
7.1.9	Effect on masculinity	135
7.1.10	Stigma	136
7.1.11	Effect on relationships	137
7.1.12	Disclosure experience and seeking support	138
7.1.13	Deciding to have an operation and the use of donor sperm	141
7.2	Learning from men's experiences and recommendations for clinical practice and future research	143
7.3	Critical reflection on the methodology of this study	149
7.4	Conclusion and summary of key findings	150
Appendix A	Patient information leaflet	152
Appendix B	Consent form	155
Appendix C	Invitation letter	156
Appendix D	Poster with information for the recruitment of participants	157
Appendix E	Semi-structure interview guide	158
References		163

## List of Tables

<b>Table 1.</b> Construction of the initial thematic framework consisted of 25 subthemes	p. 44
<b>Table 2.</b> The five broad categories of emergent themes	p. 45

## List of Figures

**Figure 1.**The analytic process of data analysis used for this study p. 42



## Chapter 1. Introduction

Having children is considered one of the most fulfilling experiences of a person's life and for most people, having children is an essential part of life. In many cultures, childbearing is recognized as a major, normative role transition for both men and women (Eunpu, 1995). In the absence of any known medical problem, most heterosexual couples expect to be biologically capable of having children. However, when these couples are confronted with the unexpected news of infertility, such discovery can have a detrimental and lasting impact on both individuals and their close family network (Eunpu, 1995). Because infertility manifests itself as an acute and unanticipated event, it may be unexplained, and can last for an indeterminate length of time, it can create overwhelming stress and test the normal coping mechanisms of individuals (Whiteford and Gonzalez, 1995). Understanding how men and women, individually and jointly, deal with infertility, is of paramount importance in enabling healthcare professionals to address couples' issues, in order to make them an integral part of a comprehensive approach to infertility treatment and support.

### 1.1 Definition of infertility

Infertility is a complex biological and psychosocial phenomenon. In biological terms, infertility is defined as 'the failure to achieve pregnancy after 12 months or more of regular unprotected intercourse' (NICE, 2013). Infertility is classified as primary, where a couple have never had children before, or secondary, where a couple have had children or achieved pregnancy previously, but are unable to conceive again. This definition implies a connection between involuntary childlessness and active pursuit of medical intervention. The use of infertility as defined in medical terminology implies an important social expectation; that people desiring children and who are unable to conceive naturally, should seek medical help to try to expedite conception (Davidová and Pechová, 2014). In the social context therefore, infertility is often presumed as the inability of heterosexual couples to conceive and have biological children naturally. For this reason, infertility cannot be approached exclusively as a biological phenomenon. Unless couples embrace parenthood as a desired social role, they would not consider themselves as infertile or present themselves for treatment. In order to therefore understand the complexity of impaired fertility, the biological as well as the psychosocial dimensions should be considered (Davidová and Pechová, 2014).

## **1.2 Magnitude of the problem and causes of infertility**

Infertility is a growing problem and exists across all cultures and societies all over the world. It affects an estimated 10%-15% of couples of reproductive age (WHO, 2013). In recent years, the number of couples seeking treatment for infertility has increased due to factors such as postponement of childbearing in women, development of newer and more successful techniques for infertility treatment, and increasing awareness of available services (Karavolos et al., 2013). A number of medical factors can cause infertility and may involve both men and women. Infertility has been generally conceptualised in society as something that primarily concerns and affects women, however recognition of male infertility has improved in recent years. Medical research shows that men and women are equally affected by infertility.

Approximately 30% of cases of couple infertility are thought to be solely due to a male factor, 40% involve both male and female factors and in 30% of cases no objective cause can be identified (Karavolos et al., 2013).

Causes of impaired fertility include structural, hormonal, genetic and certain lifestyle factors and overexposure to environmental chemicals (Karavolos et al., 2013). The major causes of female infertility include ovulation dysfunction, uterine disorders, scarring of the fallopian tubes and structural or hormonal disorders in the eggs not implanting on the uterine lining correctly. Male factor infertility is typically associated with abnormal sperm production and function or problems related to the delivery of sperm. Sperm may be immature, abnormally shaped, or unable to move properly. In addition, sperm may be produced in abnormally low numbers (oligospermia) or not at all (azoospermia) (Karavolos et al., 2013). Unlike treatments for other medical conditions which usually aim for a 'cure', infertility treatments include other possibilities such as self-definition as voluntarily child-free, fostering, adoption and changing partners (Greil et al., 2010)

## **1.3 The impact of infertility and its treatment on individuals**

The impact of infertility on individuals and the couple depend on several factors, including the experience of being raised in a family, their motivation to become a parent, personal and shared values, as well as cultural and social norms (Deka and Sarma, 2010). Infertility, unlike other medical conditions, is unique, in affecting the couple rather than an individual. It is often seen, especially in developed countries, as a 'couple's' problem irrespective of which partner may have a functional

impairment. Infertility is not a visible or life threatening condition. It is not usually accompanied by pathological symptoms, but by the absence of a desired social status. Some authors argue that it results in silent suffering, referred to as 'reproduction trauma' (Covington and Burns, 2006, Diamond et al., 2005). Because it involves an inability to achieve a desired social role, infertility is often associated with psychological distress. It is well documented that most individuals and couples find the experience of infertility and its treatment distressing, but there is no evidence to suggest that infertile individuals are more likely to exhibit psychiatric disorders as compared to non- infertile ones (Boivin et al., 2011, Eugster and Vingerhoets, 1999, Jacob et al., 2007). The reactions and emotions typically associated with infertility include anger, anxiety, loss of control, perceived personal failure, and social inferiority (Jacob et al., 2007). Feelings of grievance and guilt are also common amongst couples with infertility (Boivin et al., 2011).

Infertile individuals seeking assisted reproductive technology (ART) treatments, find the experience highly complex and stressful. Redshaw et al. (2007) found that patients report feelings of having little control over the treatment. Participants in this study described their experience of fertility treatment as an engulfing situation that dominates their daily routine. Several studies have shown that a number of patients feel intimidated by the language of reproductive medicine and by the technical aspects of infertility treatment (Culley et al., 2006, Becker et al., 2006).

#### **1.4 Gender differences in experiencing infertility**

Infertility is generally conceptualized as a stressor which affects the couple as a unit, and it is widely recognised to present psychological as well as medical challenges and difficulties to both partners within the couple (Wright et al., 1991, Golombok, 1992). To date, the majority of research has focused on gender differences in stress, anxiety and depression amongst women and men in relation to infertility (Culley et al., 2013). Research studies have looked at 'couple' infertility and its impact on women, with results suggesting that women are, to a greater extent, negatively affected by infertility than their male counterparts (Abbey et al., 1994, Daniluk, 1988, Eunpu, 1995, Peterson et al., 2006). As discussed in more detail in the next chapter, available qualitative studies are far more likely to focus on the experiences of women than those of men, and they do not differentiate the cause of infertility as male or female. In addition, they often combine the aetiology of a couple's infertility into one

variable. As a result, little is known about the actual experience of male factor infertility and its impact on men and their families (Paterno, 2008).

### **1.5 Why is there relative lack of research on men?**

The answer to this question lays both on sociological and medical factors.

Reproduction and childbearing in our society is centred around women, and therefore (in)fertility and reproduction are generally conceptualised as being a 'woman's responsibility'. Women in our society generally have the responsibility with regards to contraception, reproduction, and childbirth due to the significance of childbearing in their lives (Culley et al., 2013). This has led to the marginalisation of men in social science research and has reduced the awareness of men's experiences of infertility, making them the 'second sex' in reproduction research (Culley et al., 2013). Yet, in biological terms, in couples presenting with infertility, male problems contribute solely or partly in up to 40% of cases (NICE, 2013, Karavolos et al., 2013).

Another reason for the lack of research on male infertility is the fact that there appears to be an almost exclusive focus of medical interventions on the female body, and therefore it is not surprising that the male experience has been largely excluded from research studies. My personal experience as a doctor is that the majority of fertility services are incorporated within gynaecology departments and women appear to be the 'target' of medical interventions for both the diagnosis and treatment of infertility. Women have greater physical involvement with fertility treatment, with the role of the man often reduced to providing a semen sample on time for treatment. Therefore, the perception of men's contribution is usually the one of performing masculine roles, such as being the 'emotional rock' for their partner, and the reason for attending the consultations is because they are 'doing it for their wives' or 'going along with it' (Throsby and Gill, 2004). As a result, it is not unusual for men to be excluded from conversation during medical consultations (Meerabeau, 1991).

Another issue that makes it more difficult to engage men in research that explores their experience of infertility, is the logistical and methodological challenge infertility research (Culley et al., 2013). Women are more likely to be approached to participate in research and also appear to be more willing to participate in such research than infertile men, because they are more integrally involved in the medical investigation and treatment (Woollett, 1985). Furthermore, when studies report the distribution of male versus female factor infertility in their samples, they tend to have samples which

are skewed towards higher rate female factor infertility (Berg and Wilson, 1991). Therefore, the research appears to have been largely conducted upon samples, which are skewed towards women as well as female factor infertility.

Another contributor to the difficulty in engaging men in psychosocial research relates to the 'sensitivity' and stigma surrounding male infertility (Lloyd, 1996) or to the fact that men are more likely to resist the depiction as 'vulnerable' and 'suffering' from psychological distress (Inhorn and van Balen, 2002). This relative marginalisation of men is however decreasing, as new interventions such as intracytoplasmic sperm injection (ICSI) have made men more involved with fertility treatments (Culley et al., 2013).

## **1.6 Purpose of the thesis**

Given the prevalence of male infertility and its impairment of the life functioning of infertile individuals and their partners, as the current literature suggests, it is important for healthcare professionals to gain a better and more complete understanding of the many challenges faced by men diagnosed with infertility. So far, the experiences of men with infertility seem to be under-represented and under-reported in the current literature. Compared to the research literature devoted to the experience and impact of infertility on women, there is a clear lack of qualitative studies investigating the impact of male infertility and its treatment on men. More research that addresses the experiences and impact of male infertility is therefore needed in this distinct group.

Using a qualitative interview approach, the present thesis explores the ways in which men experience and make sense of their own infertility. As discussed above, the ability to reproduce and parenthood are generally seen as desired social roles, by both men and women. Therefore, the inability to achieve this role is often associated with emotional strain and psychological distress (Greil, 1997). Based on the assumption that having a family is a normative expectation for many men (Marsiglio et al., 2013), the main aim of the present study was to explore the attitudes of men diagnosed with azoospermia (lack of sperm in the semen) towards their own infertility.

There are no obvious biological fertility indicators in men, and male fertility is often assumed or taken for granted. Therefore, male infertility has been largely invisible, and for many men receiving the diagnosis of azoospermia could have tremendous

psychological consequences, especially if no cause for the problem is identified. Azoospermia and the potential inability to reproduce naturally was chosen as the topic of this thesis because it is the most difficult fertility problem to treat in men, for whom a sperm retrieval operation is in most cases the only hope for establishing biological fatherhood. To my knowledge, no available qualitative studies to date have examined in-depth the impact of azoospermia on men. The following general research question was defined:

*'What is the experience and impact of the diagnosis of azoospermia on men attending a fertility clinic?'*

In addition, other, more detailed research questions were defined and used as an aid memoir to help structure the interviews with fifteen men. The topics are discussed in more detail in the methodology chapter.

This study contributes to the field of male infertility by providing important knowledge on men who have reproductive concerns and who face the potential of not being able to father a child. A better understanding of men's issues and coping strategies, following the diagnosis of their own infertility, whether treatable or not, will help to shape how services to men (and couples) are delivered.

## **1.7 Summary**

Research in reproduction and infertility has traditionally focused upon women, leaving little space for consideration of men's experiences and perspectives. The purpose of this thesis is to provide an insight into men's personal experience of infertility and a more detailed understanding of men's attitudes towards male infertility and its treatment. The chapter that follows is a literature review that seeks to provide summary of the current understanding of how men experience the diagnosis of their own infertility.

## **Chapter 2. Literature review**

### **2.1 Introduction**

The aim of this chapter is to summarise the current literature on the experiences and attitudes of men towards infertility. In order to understand and fully appreciate the reaction and experiences of individuals diagnosed with infertility, it is important to examine the reasons behind which they base their desire to have children, how they value children and what satisfaction they find in them. It begins with a brief discussion of the literature investigating the desire of individuals to have children, before turning into a fuller discussion on what is known on the psychosocial consequences of the inability to have children, with emphasis of on the experiences of men. The final section provides a summary of what is currently known and highlights the unexplored areas and gaps in our current knowledge.

#### **2.1.1 *Socio-cultural aspects of reproduction and infertility***

##### **2.1.1.1 *Desire for parenthood***

Parenthood is one of the most highly valued experiences of people, but individual views and the underlying motives towards parenthood can vary. In almost all societies, fertility and parenthood are highly valued, and children are generally seen as functional for parents and the society, but the views of parents can be shaped by societal and cultural influences. No matter how healthcare professionals define infertility, couples don't consider themselves as infertile and don't seek medical treatment, unless they embrace parenthood as a desired social role (Greil et al., 2010). The value of children symbolizes the motivations for childbearing, and has an important role to play in any aspect of infertility. Parenthood may be seen as comprising economic, biological, social or affective dimensions. One or more of these may be central to an individual's desire to parent (Schoen et al., 1999). It is well established that intentions about having a child are strong predictors of fertility behaviour (Schoen et al., 1999).

The socialization process appears to promote different meanings in the role that procreation holds for women and men. Women have typically been seen as bearing a greater psychological burden when infertility occurs. Reproductive ability appears to be more central to the female identity, whereas it tends to largely reflect the virility

of the man (Humphrey, 1977, Mahlstedt, 1985). This notion is echoed in the following woman's statement:

*'I am an infertile woman...The words seemed mutually exclusive. I could be either infertile or a woman but not both'* (Menning, 1988) (p.31)

The primary role of women in most societies continues to be that of wife and mother, although these roles have become less critical for women in more recent years, especially in Western societies (Nadelson, 1982, Williams, 1987). Although the percentage of women working has increased, employment is typically viewed as a competing alternative commitment to their primary family responsibilities. Most women anticipate the experience of motherhood, and therefore their inability to conceive prohibits the achievement of this major goal in life (Gerstel, 1987).

Regardless of a man's fertility status, his primary role has traditionally been viewed as that of worker and provider; to be a father has been considered of secondary importance (Chodorow, 1999). For men, fertility may primarily be viewed as a reflection of virility and masculinity rather than providing the opportunity to parent. Although sexual prowess may be promoted as more important to men than the actual ability to procreate, coitus where there is no possibility of conception may be viewed with less worth and is sometimes portrayed as 'shooting blanks'. Therefore, the prospect of being found infertile can be quite threatening to many men (Chodorow, 1999).

Over the last few decades, a number of studies addressed the question of what motivates men and women to have children (Hoffman, 1973, Hoffman et al., 1978, Vinokur-Kaplan, 1978, Michaels, 1987). One of the earliest and most influential approaches to answering this question was the identification of the value of children to parents (Hoffman, 1973). According to this approach, the desire to have children is related to the benefits that children bring to the parents, and was classified into three main categories. Firstly, the social value those children can bring, as couples with children conform to group norms and establish a link to the society. Secondly, the emotional and psychological benefits they bring to parents, as having children enhances the feelings of competence and allows people to exercise power and influence, as well as benefits from the status attainment of their children. Finally, the potential financial security they can bring to their older parents, by contributing to the welfare of the family and providing for their parents in old age. In this approach

therefore, children are seen as a source of social, psychological, and long term economic value to their parents (Hoffman, 1973).

A collaborative, cross-cultural study, known as the value of children (VOC) study, explored the fertility-related motives of couples in different socioeconomic groups and cultural settings in the early 1970s, using the above model (Arnold and Fawcett, 1975). Findings from this study indicated that the values of children were dependent on both individual and cultural determinants, including the socioeconomic background of each country. In Western industrialized countries such as Germany and the United States, couples desired children mainly for the fulfilment of psychological needs and to accomplish personal happiness. In less developed countries however, greater emphasis was placed upon the economic and social values attributed to children. This could be because in societies without widespread social welfare systems, such as social security benefits, unemployment insurance, accessible health care, and nursing homes, children are an economic asset and represent a significant source of security in old age (Kagitcibasi, 1982, Kagitcibasi and Ataca, 2015, Nugent, 1985). In such societies, where familial interdependency and harmony are highly valued, the elderly are expected to be cared for by their family and children rather than by formal institutions. The number of children one has therefore reflects the degree of old-age security and support that is likely to have in the future (Callan, 1982, Kagitcibasi and Ataca, 2005, Kim et al., 2005). On the other hand, in Western individualistic societies where the cultural values of independence and self-sufficiency predominate, individuals are precluded from admitting dependency even on their own children (Kagitcibasi, 1982, Kagitcibasi and Ataca, 2005).

Whilst the VOC model has been a very popular approach to understanding fertility decision-making, it has been the subject of considerable criticism by some authors. Friedman et al. (1994) highlighted the difficulties associated with imputing values from survey responses. The same authors also argue that lists of values provide no mechanism for examining how individual values are interlinked. In particular, individuals are able to list values or reasons but the reasons are assumed not to influence one another; The mere listing of these values does not allow for the examination of any relationships between these individual values.

The development of assisted reproductive technologies has allowed a greater freedom of choice for couples to decide whether or not to have children. More recent

studies have demonstrated the importance of incorporating attitudes and intentions into the fertility decision-making process. They have moved from the traditional costs and benefits model, merely listing the values and costs of having children, to incorporating intentions and attitudes into parenthood decision making. These studies therefore aim not only to predict fertility behaviour, but also to understand the motives of couples seeking infertility treatment (Schoen et al., 1999, Langdrige et al., 2005).

A UK survey of white married childless couples, Langdrige et al. (2005) investigated the reasons for and against having a child and the differences between men and women. The main reasons for wanting a child were the central role of creating a family, having a child that is biologically related to both partners, the giving and receiving of love and developing a special bond with the child. Men rated 'carry on the family name', 'good for relationship' and 'fun' strong reasons for wanting a child whereas women rated one reason, 'biological drive', higher than men. Reasons against having a child for which men scored higher than women included 'less time with partner', 'emotional strain', 'interference with career', 'responsibility', and 'lack of patience', while women rated one reason, 'partner's wishes' more highly than men.

The majority of the studies exploring the meaning of infertility in different cultures mainly concentrate on women, with very little research on how men perceive infertility (Glover et al., 2009, Purewal and van Den Akker, 2007). In Western industrialized countries, parenthood is mostly desired for the expected feelings of love and happiness, while motives relating to social reasons and norms feature less prominently in published research (van Balen and Trimbos-Kemper, 1995, Colpin et al., 1998, Newton et al., 1992, Langdrige et al., 2000). In comparison, studies from African countries show the pivotal role that fertility plays in the social context, frequently linking successful reproduction with social status and wealth, and childlessness with negative social repercussions (Dyer et al., 2008, Dyer et al., 2002, Dyer et al., 2004, Hollos, 2003, Feldman-Savelsberg, 1994, Gerrits, 1997, Sundby, 1997).

Differences between men and women in their motives to have children have also been highlighted in the literature. Women place greatest emphasis on fulfilling gender-role requirements (Crowe, 1985) and greater affiliative needs of women may influence how they value children (Hoffman et al., 1978). Studies have found that becoming a mother is more important for women than becoming a father is for men

(Berg et al., 1991, Strauss, 2002). Women tended to attribute the cause of infertility internally, as a sense of personal failure, whereas men attribute fertility problems to an external source (Andrews et al., 1992).

Men, having more diverse life opportunities, have been described as being 'disappointed but not devastated' by the inability to have children' (Strauss, 2002) and they are more likely to stress a desire for marital completion and embrace economic parenthood more readily than social or affective parenthood (Greil et al., 1988). These differences in motives also translate to differences in the psychological reaction between men and women who are involuntary childless. Greil (1997) reported that stereotypically, women are presumed to have a greater desire to have children and therefore to experience grief when the life goal of motherhood (a non-event) does not materialise.

Women regard infertility as a major problem in their lives, whereas men regard fertility problems as having the same priority as other stressors in their lives (Andrews et al., 1992). Studies have highlighted the extremes to which infertile women will go in order to have children, including undergoing risky medical procedures with unknown long-term side effects (Inhorn, 1994). This is because of the cultural value given to motherhood as a woman's most important role. However, comparable information on the lengths to which men will go to father a child is lacking. In a study of 108 infertile couples, over 20% of women and 7% of men said that they were willing to give up everything to have children, with 30% of women and 28% of men willing to give up a great deal to have a child (van Balen and Trimbos-Kemper, 1995).

In a population-based survey of 1580 people in Germany, equal numbers of men and women aged 31-40 expressed the desire to have a child (Stobel-Richter et al., 2005). This desire was based on the wish of both men and women to create new life, form a family and experience love. A similar survey in the UK investigating the intentions and motivations for parenthood 874 couples, found no overall differences between men and women in their intention to have a child (Langdrige et al., 2005). Results of the study indicated a number of reasons to be particularly important in predicting intentions to have a child. These included the central role of becoming a family and having a child that is biologically related to both parents and a strong emphasis on values concerned with primary group ties and affection such as the giving and receiving of love, as well as the special bond that develops between a parent and child. In addition, men's predominant reasons for wanting children were the

continuation of the 'family name' and the 'fun' and pleasure of having a child, in contrary to women who rated the biological drive for motherhood as the strongest reason.

It appears that the underlying motives for parenthood vary between individuals and between societies. Despite the availability of adoption and donor insemination, many couples maintain a strong preference for biological children. This focus on genetic ties may be even more prominent among certain ethnic groups given the importance of family bloodline in some cultures and the pressure for men to fulfil their paternal duties to the family. Consequently, being diagnosed with male factor infertility can be a very devastating and traumatic experience for these men.

### **2.1.1.2 Gender, masculinity and infertility**

To gain a better understanding of men's experience of infertility, it is important to first examine the meaning of gender, gender identity and gender role, and the relationship between masculinity and infertility.

#### **2.1.1.2.1 Gender and masculinity**

Gender can be defined as the psychological, behavioural, and cultural characteristics that typically distinguish men and women (Maltby, 2005). Gender activities can be viewed as either masculine or feminine in nature. Gender identity refers to an individual's internal and subjective sense of self as a man or a woman, and it reflects the degree to which a person identifies with or displays societal definitions of masculine or feminine behaviour (Cohen, 2001). Gender adequacy pertains to an individual's self-judgement of his or her adequacy as a man or a woman. People's sense of self as male or female often guides the way in which they see themselves and interact with others, as well as the attitudes and social expectations they create (Kimmel, 2004).

Gender role is defined as the outward expression of gender identity and is a socially-based distinction, often subject to individual interpretation. It refers to the set of attitudes and behaviours that are considered normal and appropriate in a specific cultural setting, for people of a particular sex (Kimmel, 2004). It is now generally accepted that gender role is not 'given' biologically, but rather shaped by a variety of biological, psychological and socio-cultural factors (Kimmel, 2004). When one assumes a particular role it invariably has a gender cast attached to it. For example,

phrases like 'boys don't cry' reflect dominant notions of masculinity and how boys should behave. Such expectations tell us which behaviours are appropriate, acceptable, or anticipated in the context of a given situation (Cohen, 2001). Male cross-gender behaviour appears to be treated more harshly than female cross-gender behaviour. If individuals change their roles by assuming a cross-gender activity, it is likely that they will be viewed negatively in society (McCreary, 1994).

Masculinity ideology is an individual's internalization of cultural beliefs and attitudes towards men's roles (Levant and Richmond, 2007). The masculine gender role informs expectations for men to conform to certain socially sanctioned masculine behaviours and avoid certain feminine behaviours. The masculine role suggests that men are characteristically more self-directing and goal-oriented than women, and see themselves as active doers (Parsons, 1954). Personality traits manifested by men and reflecting this role include independence, assertiveness, and decisiveness. These characteristics assist men in fulfilling their traditional roles in society. The six main attributes which have been consistently found to be associated with masculinity include aggression, violence, physical prowess, dominance, success and achievement. Men typically present themselves as confident, strong, self-reliant and reluctant to express their affection (Boles, 1982).

Pleck (1995) proposed that there is a complex set of standards and expectations that define the traditional male role in our society throughout most of the world, which has been referred to as the 'traditional masculinity ideology' (Pleck, 1995). Based on this theory, Levant et al (2007) developed the Male Role Norms Inventory (MNRI), which measures 7 theoretically-derived norms of traditional masculinity ideology: avoidance of femininity, restrictive emotionality, achievement and status, self-reliance, aggression, homophobia, and non-relational attitudes toward sexuality. Subsequent research on masculinity ideology using the MNRI showed that men tend to endorse traditional masculinity ideology to a greater extent than women (Levant and Richmond, 2007). Deviations from these gender role expectations, therefore, are more threatening to men's sense of gender identity as compared to women. Moreover, individuals with a high gender role salience are more likely to devalue themselves, and experience loss of self-confidence and sense of self-worth (O'Heron and Orlofsky, 1990).

Research indicates that the male stereotype is more rigidly defined and enforced in our society than the female stereotype (Hort et al., 1990). In other words, people's

perceptions of 'male' appear to be more stereotypically framed than their perceptions of 'female'. This idea is also supported by a study which explored the differences in gender role expectations amongst 526 college students (Wentworth and Chell, 2001). In this study, men showed higher levels of endorsement of traditional gender roles and gender role expectations than women. As such, men are likely to experience more stress when they feel they are not meeting cultural expectations of masculinity, or when a situation forces them to act in feminine-typed ways (McCreary et al., 1996).

#### **2.1.1.2.2 *Masculinity and infertility***

While discussions of masculinity have been central to a number of disciplines for a number of years (Throsby and Gill, 2004), only few contributions have been devoted to the association between male infertility and masculinity. The few available studies indicate that the sense of masculinity and the capacity to be a biological father can be intricately interrelated in men. Expressions such as 'that takes balls', 'he shoots blanks' or 'grow a pair' illustrate the prevailing cultural belief that healthy testicles and male reproductive potential are symbols of strength, courage, power, manliness and masculinity (Barnes, 2014). The normative construction of masculinity idealizes the male physique as vigorous and robust, which is often indicated through physical and/or sexual prowess. The cultural expectations of masculinity are that the ideal man is considered virile, potent and able to have sex and impregnate a woman when he so desires (Potts, 2000). The general consensus appears to be that 'being able to get your wife pregnant is like the whole point of being a man' (Barnes, 2014). Failure in this domain therefore could reflect a form of inadequacy for some infertile men.

When in 1992 researchers from Denmark announced a worldwide fall in sperm counts of more than 40 percent over the preceding 50 years, an international fertility 'crisis' was perceived by the media (Carlsen et al., 1992). Over the following few years, smaller studies on male infertility proliferated across individual nations. Sperm counts were believed to provide a measure of national masculinity, to a point where sperm counts of nations were being compared in Olympic competition terms (Daniels, 2006). Some media coverage depicted this as 'lack of national virility', threat of rising female power and highlighted the cultural value of virility and the centrality of virility to cultural ideas (Barnes, 2014).

It is evident therefore that male factor infertility threatens a traditional fundamental part of the masculine gender role, and can cause men to be more apprehensive about their masculinity, and reassess their values and personal masculine identities as husbands and fathers-to-be. This can have a negative impact on some men's psychosocial wellbeing, as they come to terms with their inability to perform one of the most important masculine functions (Lee, 1996, Throsby and Gill, 2004, Meerabeau, 1991, Owens, 1982, Barnes, 2014). Some researchers have found that men's apprehensions about their masculinity are far more likely when they are diagnosed with infertility themselves as compared to couple infertility, because power and potency are traditionally linked with a man's ability to reproduce (Elliott, 1998). Throsby and Gill (2004) found that when men are diagnosed with infertility, their level of distress is as high as that of infertile women. This may be partly due to fact that the dominant social construction of masculinity is defined in terms of the ability to father a child rather than parenting per se (Throsby and Gill, 2004). Infertile men report that the diagnosis of infertility strikes at the core of their self-concept of sexual potency (Elliott, 1998). They described the feelings of being robbed of their masculinity, not being a 'real man,' feeling unable to provide for their wives or making their partners happy (Berg et al., 1991). Some authors, on the other hand, have found that some men are able to either separate themselves from these issues or they don't draw their sense of identity and masculinity from their ability to procreate (Elliott, 1998).

## **2.2 Men and help-seeking**

Popular stereotypes portray men reluctantly asking for help or consulting a manual when they can't complete a task, asking for directions when they are lost, having difficulty sharing vulnerable feelings with family and friends and being less likely than women to seek professional help for physical and mental health problems (Addis and Mahalik, 2003). Evidence from several studies also shows that medical care utilization by men across different ages, social and ethnic backgrounds is lower than women. Men make fewer contacts with their general practitioners and other health care professionals than do women (Gijsbers van Wijk et al., 1992, Jackson, 1991, Griffiths, 1992, Neighbors and Howard, 1987, Rafuse, 1993), and when they ask for medical help, they tend to have fewer questions than do women (Courtenay, 2000). Men also seek help for depression, physical disabilities and stressful life events less often than women (McKay et al., 1996, Padesky and Hammen, 1981, Thom, 1986,

Weissman and Klerman, 1977). Findings show that men are less likely to seek help for problems relating to substance abuse as compared to women (McKay et al., 1996, Thom, 1986). This is despite men reporting higher levels of substance abuse (Kessler et al., 1994) and being more likely to experience psychosocial problems as a result of alcohol and drug abuse compared to women (Robbins, 1989). Research also confirms that men seek psychiatric help, psychotherapy and counselling less often than women (Gove, 1984, Gove and Tudor, 1973, Greenley and Mechanic, 1976, Howard and Orlinsky, 1972, Vessey and Howard, 1993). With regards to infertility, women are more accustomed to seeking help as compared to men. Women are often the first to recognize infertility as a problem and to initiate discussion and seek further investigation and treatment (Berg et al., 1991). The majority of initial referrals are made to the woman's gynaecologist rather than to the man's urologist or to the gynaecologist with both attending an infertility clinic (Berg and Wilson, 1991). This however might have changed in more recent years with the development of clinics specifically addressing infertility as a problem, and consulting patients as a couple. The greater number of diagnostic tests and treatments that continue to be available for infertile women as compared to men, further contributes to the medical focus upon women once the couple has begun an infertility work-up (Berg and Wilson, 1991).

But why do men find it more difficult to seek professional help? Despite consistent documentation that men seek help less often than do women, there is little evidence to explain why this is so. In the past, men's low rates of help seeking for problems were considered normal, because it was believed that women were over-utilizing services, by being weak and hypochondriac, while men, being the stronger sex, were using services only when it was really needed (Courtenay, 2000). Addis and Mahalik (2003) argued that men are less likely to ask for help because this involves admitting to areas of weakness and focusing on vulnerable emotions; tasks that are inconsistent with the traditional masculine gender roles of being self-reliant and emotionally controlled. For example, a man who generally conforms to the norm of emotional stoicism is likely to feel that seeking help for depression, for example, is a threat to his self-esteem.

Given the potential impact of the infertility diagnosis for either gender, some couples are seen as reluctant to pursue further investigation and treatment. While many factors may contribute to this reluctance to seek help (e.g., lack of desire, limited

finances, etc.), difficulty facing a definite diagnosis of infertility may be one of them (Berg et al., 1991).

Some authors have suggested that people are less likely to seek help when a problem is perceived as ego-central. Ego-central problems are defined as those perceived to reflect an important quality about oneself (for example intelligence if one is an academic or physical strength if one is an athlete). Tessler and Schwartz (1972) found that if participants believed that many other people failed at a task they were asked to complete (i.e., that failure was normative), help-seeking became more likely. However, if participants believed that few other people failed at the task (i.e., that failure was non-normative), they were less likely to seek help.

Mahalik et al. (2003) proposed that men are influenced by gender role norms, in a similar way that social norms influence people to engage in specific social behaviour. Masculine gender norms operate when a man observes what most men are doing in a social situation; 'he' sees what acceptable or unacceptable behaviour is for men and observes how popular men act. Thus, conformity to masculine norms is defined as meeting societal expectations for what constitutes masculinity in one's public or private life (Mahalik et al., 2003). In this way men may experience barriers to seeking help from health professionals depending on how they perceive others' reaction around them if they decide to seek help. This is especially true if other groups of men around them express similar attitudes, and when they see themselves as quite similar to these groups of men that they consider important (Addis and Mahalik, 2003). For example, if a man is considering seeking help for his depression, it is likely that he would keep his depression to himself and not seek professional help if the men with whom he works have never mentioned the problem and regularly make statements about the importance of staying strong, and not letting things get them down. However, if he also belonged to a large church group in which men were encouraged to share problems with friends, family members, and other members of the church, he might be more likely to mention his problem and seek help (Addis and Mahalik, 2003).

The reasons discussed above could also explain the reluctance of men to seek psychological counselling. Available research indicates that women are more receptive to psychological counselling than men (Daniluk, 1988, Wischmann et al., 2001, Wischmann, 2008, Baram et al., 1988). This could be because women are more predisposed to adopting a coping strategy that is based on social support

(Abbey et al., 1992, Stanton et al., 1992). However, there are only a small number of dated studies examining this point and therefore more research is needed in this area (Wischmann et al., 2009).

## **2.3 The impact of infertility on men**

Infertility itself is more than just a medical condition and its experience can affect individuals in different ways. This section provides an overview of the potential losses and gains associated with the diagnosis of infertility, as well as the physical and psychological impact of infertility on both the individual and the couple.

Infertility has traditionally been viewed as a female problem in both from a physical and psychological aspect (Berg et al., 1991). In some societies, myths have persisted that infertility results solely from problems in the woman. Yet, actually, as previously discussed, in a large proportion of cases infertility results from a combination of both male and female factors (NICE, 2013).

The diagnosis of infertility, the search for identifying the cause(s) and obtaining successful treatment is often physically and emotionally overwhelming for the individual and the couple. Infertility can affect how individuals feel about themselves, their relationships with their partner and family, and their life perspective in general (Hart, 2002).

### **2.3.1 *Physical impact of infertility and infertility treatment***

Infertility investigation and treatment puts enormous pressure on couples. Among infertile couples, women usually undergo the majority of fertility tests and treatments which cause discomfort and therefore it is generally thought that only women's bodies are physically involved whereas men 'escape' the negative physical consequences of infertility. However, as discussed below, this may not be true because infertility can have a toll on both men and women.

#### **2.3.1.1 *Undergoing investigation and treatment***

Women are centrally involved in the great majority of diagnostic and treatment procedures in an infertility investigation. Even in cases of male factor infertility, procedures like artificial insemination are often pursued which still require substantial involvement of the woman. As such, the physical (and psychological) discomfort associated with these procedures can affect women to a much greater degree, even

in cases of male factor infertility (Berg et al., 1991). Some authors have suggested that women's bodies are particularly 'permeable' during ART treatments, whereas men's bodies, by contrast, seem to remain relatively 'stable and untouched', even when male infertility is the cause (Van der Ploeg, 1995). This however may not be true. Infertility investigation and treatment can have an effect on men as well as women. During the assessment, men often undergo a painful journey, during which time virtually every aspect of their intimate lives is subject to scrutiny. Apart from having to answer personal questions, men often have to be examined intimately, especially if diagnosed with their own infertility. Sexuality, an intimate area of men's lives, which once was spontaneous and private now becomes clinical systematic and planned, talked about by medical staff as though they were discussing common things (Atwood and Dobkin, 1992).

Very little is known about how men experience treatment for their own infertility, even in relation to procedures that are uniquely related to them, such as semen sample production and surgical sperm extraction (Culley et al., 2013). Men have to provide semen samples by masturbating into special cups to test for sperm counts. Indeed, the need to obtain sperm for ART treatment can lead to psychological trauma for some men (performance anxiety), who are unable to successfully ejaculate through masturbation, and physical trauma for other men that have to undergo surgical sperm retrievals (Inhorn, 2007). In addition, there is lack of research on how men (and their partners) decide whether to undergo or not invasive sperm retrieval procedures before ART treatment, and on their experience of undergoing such procedures. A number of studies evaluated specific aspects of the quality of care provided to such men (Gorgy et al., 1998, Ezeh et al., 1999, Wood et al., 2003, Nudell et al., 1998), nevertheless, these studies have not provided an in-depth insight into men's perspective on such care (Dancet et al., 2010).

### **2.3.1.2 *Infertility and male sexual function***

The prevalence of sexual disorders in infertile couples remains unclear (Tao et al., 2011). A review of recent literature on the impact of infertility on sexuality, found that authors frequently reported a positive association between the diagnosis of infertility and sexual dysfunction for both men and women (Tao et al., 2011). Studies report reduced sexual satisfaction and loss of spontaneous sexuality amongst partners during the experience of infertility, with women reporting less satisfaction than men, irrespective of the fact whether the cause of infertility is male, female, mixed or

unexplained (Wischmann et al., 2009, Lee et al., 2001, Sultan, 2011, Hirsch and Hirsch, 1989).

The results concerning men's sexual function in connection with infertility show that erectile dysfunction and premature ejaculation are more common in infertile men undergoing fertility treatment as compared to fertile men (Wischmann, 2013, Inhorn, 2007). These problems are often the result of loss of interest or the stress and psychological pressure experienced when trying to conceive or cope with infertility (Elliott, 1998, Berg et al., 1991, Atwood and Dobkin, 1992, Monga et al., 2004, Akbal et al., 2010). Indeed, some researchers have termed this 'iatrogenically imposed impotence' resulting from the demands of sexual performance imposed by infertility treatment in some couples (Rantala and Koskimies, 1988).

In a study looking at the effects of the outcome of testicular sperm extraction in non-obstructive azoospermic men, the authors found that unsuccessful TESE procedures have a negative effect on sexual function because of psychological as well as hormonal (low testosterone) reasons (Akbal et al., 2010). Failure to surgically recover sperm might put an end to all hope for male patients who wish to become a biological father (Akbal et al., 2010).

Bain (1993) reported that in up to 80% of men diagnosed with male factor infertility, sexual dysfunction was a bi-product of the diagnosis. The authors concluded that for men, the emotional experience of infertility can be more easily expressed in their sexual functioning. Berger (1980) found that 10 out of 16 men had experienced impotence upon discovering their azoospermia. This was regarded this as an interactional problem of the men with their partners, which was transient and lasted for up to 3 months. These findings were also supported by other authors, who found that men reported higher rates of premature ejaculation, erectile dysfunction (Gao et al., 2013) and sexual dissatisfaction (Schmidt, 2006, Gulec, 2011) upon the diagnosis of male factor infertility. A recent review of 14 studies also concluded that men participating in fertility treatments have an increased rate of erectile dysfunction (Ferraesi et al., 2013).

On the other hand, Kedem et al. (1990) reported that men with suspected infertility don't necessarily report more erectile or ejaculatory difficulties, sexual disinterest or loss of pleasure during sex, as compared to men in the general population (Kedem et al., 1990). The available literature therefore, reveals contradictory findings about the direct impact of infertility on sexual function in men.

## **2.4 Psychosocial impact of infertility**

### **2.4.1 Theories that explain the psychosocial impact of infertility**

Many theories have been proposed to explain the psychosocial impact of infertility on individuals and couples (Burns, 1999). Two of these, the life-crisis theory and the biopsychosocial theory are discussed in more detail in this section.

Menning (1977) proposed the *life-crisis theory* of infertility, based on the grief model used with dying patients and their close family. A life crisis is defined as the occurrence of an unexpected event that negatively affects the recipient. A crisis may also be because of the lack of an expected transition, otherwise known as a 'non-event' (Schlossberg, 1995). Parenthood is considered as a rite of passage similar to puberty, marriage, and retirement. Therefore, the inability to achieve parenthood and fulfil personal and societal goals can cause a life crisis (Berk and Shapiro, 1984, Forrest and Gilbert, 1992, Menning, 1977, Williams et al., 1992). Many individuals who are subsequent found to be infertile, have made a decision to have children, only to find that they are unable to do so. This non-event can result in the loss of a role that for some is the most important in their lives.

The life-crisis theory views infertility as a major negative event and focuses on the consequences of being infertile (Donnis, 1984, Menning, 1977). Proponents of this life-crisis model believe that most couples that struggle with infertility are mentally healthy and that the preponderance of infertility is physically based, even for those with idiopathic or unknown aetiology. However, infertility also may increase anxiety and stress and negatively affect coping skills (O'Moore et al., 1983). The effect that infertility has on an individual depends on his or her type of personality, coping style and motivations for having children (Batterman, 1985, Blenner, 1990a). Some authors have suggested that the initial crisis often changes to a chronic condition and requires additional long-term interventions (Berg and Wilson, 1991, Forrest and Gilbert, 1992).

The *biopsychosocial theory* (Pasch, 1997) originates from the stress and coping model and describes infertility as an event that affects individuals, couples and families in various stressful ways. As Gove (1982) describe it, this theory depicts human experiences as 'a complex interaction of the biological, psychological, and social phenomena'. This theory attempts to explain human behaviour in a way that addresses the interaction of these different factors. The biological aspect focuses on

the impact of infertility on an individual's body, as a physical stressor. The psychological aspect refers to the behavioural and mental impacts of infertility as emotional stressors on individuals and infertile couples. Individual's and couple's experience of infertility is also influenced by the structures and organizations of their society, leading to existential and interpersonal stressors. What is impacted is the sense of self, and a person's relationships with his/her partner, family, and friends. According to the biopsychosocial theory, infertility impacts into four stressors: 1) existential, 2) physical, 3) emotional, and 4) interpersonal (Gerrity, 2001a). These are discussed in more detail below.

There is evidence from research that infertility impairs infertile couples' existential role of participating in the continuity of their family, their community, and their culture. The experience of being infertile can influence an individual's sense of identity, self-esteem, and stigma (Gerrity, 2001a). Meyers *et al.*, (1995) wrote:

*'Children provide existential meaning, identity, and status; they grant parents the traditional means of participating in the continuity of a family, a culture, and the human race' (p. 231).*

Identity reflects an individual's concept and expression of self. Research supports that among infertile couples, women experience a greater identity crisis than their male counterparts. Greil *et al.* (1988) found that husbands and wives responded radically different to the diagnosis of infertility. Wives experienced infertility as a cataclysmic role failure that spoiled their ability to live normal lives. They found that women became very focused on the problem of infertility and thought about infertility often, read about it constantly, and were often willing to do whatever it would take to shed the infertility status (Greil *et al.*, 1988). The husbands tended to see infertility as a disconcerting event, but not as a tragedy. They were likely to feel that it was something they could accept and put into perspective and were wondering that their wives could not do this as well. While the wives tended to be interested in overcoming infertility no matter what it took, their husbands were more interested in returning to normality, whether this implied pursuing treatment or ceasing treatment. These gender specific patterns were found regardless of which partner was found to have the fertility impairment.

In pronatalistic and patriarchal societies, it is evident that women often bear the brunt of the social, emotional and physical consequences of childlessness, irrespective of who of the partners has the reproductive impairment. A qualitative study exploring

the experiences of couples with male infertility in Egypt (Inhorn, 2003), found that the femininity of the women was impaired even though they were not responsible for the infertility, as their motherhood could only be realized through childbearing. However, the masculinity of the infertile men was not seriously affected by their infertility. Egyptian women in childless marriages typically experience procreative blame, even when male infertility, referred to as 'weak worms' is socially acknowledged. In addition, Egyptian women married to infertile men experience diminished gender identity and threats of male-initiated divorce. Although male infertility also presents a crisis of masculinity for Egyptian men, this crisis is not as pronounced, because men had alternative ways to manifest their masculinity, through achievements at work or in sports. The impact of male infertility often redounds in multiple ways on the lives of women, who ultimately pay the price for under conditions of Middle Eastern patriarchy (Inhorn, 2003).

A more recent qualitative study conducted in Pakistan, reported that the social identity of fatherhood is not as important for men as the social identity of motherhood is for women (Mumtaz et al., 2013). Childlessness is invariably blamed on the female partner by everybody concerned; the husband, marital family and society in general. Men in childless marriages view themselves, and are seen by society, as inert, usually innocent partners. Pregnancy and childbirth are considered women's domain only. Men in this study had little to say on the matter and their interviews lacked the depth and pain evident in women's interviews (Mumtaz et al., 2013). Data also shows that childlessness in Pakistan greatly weakens marital bonds since children are believed to strengthen the marital bond (Qadir et al., 2005). Weak marital bonds are more detrimental for women compared to men. Childless women considered themselves as 'kamzoor' women, women with weak social ties with their marital families. The study concluded that childlessness does not affect men the same way as they do women in Pakistan, because men's social identity does not hinge on the strength of their marital ties (Qadir et al., 2005).

Self-esteem represents a person's appraisal or evaluation of his or her own worth. Infertility may threaten self-esteem due to its potentially stigmatizing nature (see below). The impact of infertility on self-esteem has been explored by a number of studies, which conclude that among infertile couples, females tend to have lower self-esteem than their male partners, especially in cases of female infertility (Lee and Sun, 2000, Lee et al., 2001, Wischmann et al., 2014, Bernstein et al., 1985). Self-

image is also affected (Abbey et al., 1994, Atwood and Dobkin, 1992), with individuals diagnosed with infertility frequently feeling defective, unattractive, and unacceptable to others (Batterman, 1985, Valentine, 1986). Loss of pride, confidence, optimism and life satisfaction is often reported (Abbey et al., 1994, Bromham et al., 1989, Link and Darling, 1986). The failure to conceive raises doubts for the individual about competencies in other roles, such as parenting and marital relationships (Greil et al., 1988).

A number of studies have explored stigma perception by infertile couples. Stigma refers to the negative sense of social difference from others and from cultural norms, and can be both deeply discrediting and devaluing to the individual. Generally, social constructs portray the idea that couples should have and want to have children (Miall, 1994). Childlessness is therefore considered to be non-normative, deviant, and thus potentially stigmatising for individuals. Research findings indicate that infertile females, especially in certain cultures, experience a greater degree of stigma than infertile males, and that stigma perception in women leads to higher distress levels and lower perceived support (Slade et al., 2007, Ying et al., 2015). In certain communities, the degree of stigma related to infertility is higher. Dimka and Dein (2013) found that women of infertile couples in Nigeria endured more verbal and physical abuse than their partners (Dimka and Dein, 2013). Another study in Pakistan revealed that the stigma of infertility was more painful than the infertility itself, and that this stigma was gendered, with women facing greater stigmatization than their husbands, even in cases of male infertility. Childless females were usually excluded from taking part in societal rituals, such as wedding celebrations and gatherings to celebrate a new born baby, while men were never similarly treated (Mumtaz et al., 2013). The study conducted in South Africa also indicated that, under the influence of patriarchy, male infertility was always kept a secret. Hence, the husbands of infertile couples were exempted from the stigma of infertility while their wives suffered, including by being called certain names and being blamed for infertility (Mabasa, 2002). It therefore appears that in couples suffering from infertility, women perceive a higher degree of stigma than men (Slade et al., 2007). This could be because infertile males are considered more stigmatized by infertility than infertile females, and therefore the blame of infertility is pointed towards the females (Miall, 1994).

Infertility is considered to be a concealable stigma, since it is not immediately apparent. However, as time passes, being childless becomes a potentially stigmatising attribute and draws attention to the fact that a couple haven't got children (Miall, 1985). People with concealable stigma are constantly engaged in a process of worrying about information giving. They need to decide whether to tell anyone about their problem, as well as when and to whom to disclose their problem. Couples without children are routinely asked 'why', and the issue of whether to disclose the fertility problems is a difficult decision facing them and can lead to considerable stress (Whiteford and Gonzalez, 1995). Research indicates that infertile individuals often perceive their childless status as stigmatizing and think that disclosure of their fertility problems would lead others to think less of them (Miall, 1985). Infertile women in particular report avoiding encounters that act as reminders of their own infertility. For example, they find it difficult to spend time around children or pregnant women, which can make them suspend friendships and avoid family gatherings (Miall, 1986).

#### **2.4.2 *Infertility and psychological distress***

There are a number of studies that assess the effect of infertility on the psychological functioning of individuals (Daniluk, 1988, Link and Darling, 1986, O'Moore et al., 1983, Slade et al., 2007, Valentine, 1986, Edelman and Connolly, 2000). Given the biological differences between the two sexes, and also the differences in the socialisation processes and gender-role expectations discussed above, it would be reasonable for one to suspect that females and males may experience the diagnosis of infertility and adjust to it in different ways. Most of the available research concludes that women experience greater psychosocial distress and lower self-esteem as compared to men (Holter et al., 2006, Jacob et al., 2007, Jordan and Revenson, 1999, Elliott, 1998, Anderson et al., 2003). Women also tend to suffer more from psychiatric disorders in general (Abbey et al., 1994, Gibson and Myers, 2000, Hjelmstedt et al., 1999) and experience more anxiety and depression, more psychosomatic symptoms and greater sensitivity related to the diagnosis of infertility (Peterson et al., 2006, Pasch et al., 2002).

However, the above-mentioned research studies are far more likely to focus on the experiences of women than those of men, and tend to reinforce the differences between the two sexes. Some authors argue that this finding that women react more adversely to infertility is overly influenced by outdated gender stereotyping

(Edelmann and Connolly, 2000). Studies often combine the aetiology of a couple's infertility into one variable. There are very few studies that take into account the cause of infertility as male or female. The majority of these report that the relationship between gender and infertility distress is not affected by which partner has the reproductive impairment (Greil, 1997). One study found that both men and women facing male infertility reported higher global stress than men and women experiencing female infertility (Newton et al., 1999).

Little is currently known about the actual experience of male factor infertility and its impact on men's psychological wellbeing (Paterno, 2008). There is a growing body of research suggesting that the diagnosis of 'male-factor' infertility is the one situation that appears to have a more negative male response to infertility, as compared to the diagnosis of unexplained, mixed or female infertility (Daniluk, 1997, Leiblum, 1993, Hinton and Miller, 2013). Evidence indicates that men of reproductive age have similar desires to experience parenthood to those of their female counterparts (Fisher and Hammarberg, 2012).

In a society where manliness is defined to a great extent by strength, power, and virility, many men, learning of their diagnoses of infertility, feel shamed and humiliated before themselves and their partners (Keylor and Apfel, 2010).

Consequently, infertile men often report feeling the loss of self-esteem and identity as a man, husband, and potential father (Peterson et al., 2003), have a higher incidence of anxiety, depression (Ahmadi et al., 2011, Folkvord et al., 2005, Gao et al., 2013), stress (Peronace et al., 2007), and report a poorer quality of life as compared to fertile men (Klemetti et al., 2010). Infertile men are also less likely to talk openly about their experiences and feelings toward infertility (Nachtigall et al., 1992, Inhorn, 2003). While women are better able to express their feelings toward infertility, many men struggle with their own emotions and feel both helpless in trying to comfort their spouses, and frustrated at not being able to solve their own infertility and help their partners get pregnant (Peterson et al., 2006, Daniluk, 1997).

### **2.4.3            *The effect of infertility on relationships***

#### **2.4.3.1        *Impact on the partnership***

Family systems theorists have long considered childbearing to be a major family transition and to be a distinct stage in the family life cycle (Carter, 1980). Individuals hope that becoming a parent will provide a sense of completion or fulfilment that

being a husband or wife somehow did not provide (Langdridge et al., 2005). Some authors argue that the motivation of couples to have children comes from the need to fill a 'void' or the need to avoid facing problems in their relationship. They see therefore having children as a way to 'bridge the gap' between themselves (Langdridge et al., 2005). Children are often seen as an acknowledgement of a couple's commitment to one another and this could mean that children make a marriage happier and less susceptible to divorce. The stress of infertility and the inability to have children can therefore cause tension in couples' relationships and increase the tendency for breakdown (Mikesell, 2003, Greil, 1997).

Research findings on the effect of infertility on marital happiness, including gender differences in marital satisfaction, have been varied and inconsistent. On one hand, studies report a lower level of satisfaction by both partners, with no significant differences between women and men (Wischmann et al., 2009, Sultan, 2011, Verhaak, 2003). Some studies report that women were less satisfied than men with their marriages (Lee et al., 2001, Bell, 1981). Others found that women had higher levels of marital adjustment and satisfaction than men, but scores for both sexes fell within normal ranges (Daniluk, 1988, Freeman et al., 1987). Newton et al. (1999) reported that relationship concerns related to infertility were more effective predictors of depression and marital dissatisfaction than expressed needs for parenthood or attitudes toward child-free living (Newton et al., 1999). Others also report that infertility can have a negative effect on the quality of life of individuals and can cause serious strain, and sometimes a breakdown on couples' relationships (Greil, 1997, Chachamovich et al., 2010). One study reported that marital adjustment was lower in couples who were infertile when the man had the reproductive problem (Nachtigall et al., 1992).

However, other studies had contrary results, which suggest that infertility is a situation that can strengthen couple's marriage and improved couple's mutual connection (Cserepes et al., 2013, Edelman and Connolly, 2000, Galhardo et al., 2013, Onat and Beji, 2012, Schmidt et al., 2005, Daniluk, 2001). Schmidt et al. (2005) defined a new concept in relation to the impact of infertility on a couple's relationship, referred to as the 'marital benefit'. The authors define this as the positive effect of infertility on the satisfaction rating of the marriage. In a prospective cohort study, they looked for factors that enhance infertile couple's relationship, and found that around two-thirds of the participants strongly agreed or somewhat agreed

that the infertility had brought the partners closer together and/or had strengthened the couples' relationship (Schmidt et al., 2005). Among the predictors studied, they found that keeping the infertility and its treatment as a secret, was a significant predictor of low marital benefit for men. Similar findings have been reported by other authors who found that men who did not communicate their infertility problem to others showed a lower level of long-term well-being overall (average length of infertility 8.6 years), compared to those men who did talk about their infertility (van Balen and Trimbos-Kemper, 1994).

Peterson et al. (2003) explored the impact of congruence between partner's perceived infertility-related stress and its effect on marital adjustment in infertile men and women. They found that infertile individuals who perceived equal levels stress in a relationship, reported higher levels of marital adjustment as compared to individuals in couples who perceived the stress differently (Peterson et al., 2003). They concluded therefore that high levels of agreement between partners, in relation to the stresses they experience, help them successfully manage the impact of these stressful life events. Abbey et al. (1995) also found that increased received emotional support between the partners of infertile couples was related to increased marital life quality.

#### **2.4.3.2 *Impact on relationship with family and friends***

A prospective cohort study conducted in Edinburgh, Anderson et al. (2003) found that females were more likely than males to avoid being around friends who had children or who were pregnant. The authors concluded that no change was found in this gender difference after 6 month's follow up. This study however did not differentiate between the causes of infertility as male or female. Another study involving 633 females and 535 males found no gender differences in the satisfaction with friends, acquaintances, and relatives in couples attending infertility counselling (Wischmann et al., 2009).

#### **2.4.3.3 *The sense of loss associated with infertility***

Individuals and couples diagnosed with infertility, and their close family, experience many tangible and intangible losses because of their inability to conceive. Firstly, there is the devastating loss of a potential biological child for the couple and the loss of genetic continuity. Women report missing the biological and social experience of being pregnant, including wearing maternity clothes, swelling of their abdomen, the

birth of the child and breast feeding. Other losses include the loss of one's self image as a fertile person, lost imagination about being a family, the loss of the opportunity to move to the next stage in the family life cycle, relationship losses, the loss of the parenting experience and bringing up a child and the loss experienced by other family members such as potential grandparents (Mahlstedt, 1985).

Many couples have thoughts, feelings, and images about pregnancy, birth and raising their children. These range from decorating a baby's room, to buying baby clothes, to cutting the umbilical cord. One husband from a couple diagnosed with infertility, described his experience as follows:

*'I have always imagined being there at the birth, video camera in hand. I even bought a new camera last year when we thought we would be pregnant. Now I feel I should return it, but that would seem like we were giving up'* (Jaffe et al., 2005, p. 50).

Each month, when the woman starts menstruating, the couple may experience a deep sense of loss; a loss of an imagined pregnancy. As time goes by, this sense of loss deepens, and many couples report that their hope of conception seems to fade. Couples go through life as though there is 'a dark cloud above their heads' and experience a feeling of impending doom. When they are eventually discover the diagnosis of infertility, their worst fears become true (Atwood and Dobkin, 1992).

Although the loss of infertility and the grieving process has been described to be similar to the loss of a loved one (see section 2.4.1), some authors argue that the 'losses' surrounding infertility ( a non-event) cannot be compared to the loss of a person (Cudmore, 2005). This is because in the case of infertility, a baby was never conceived, and therefore there are no memories to recall. On the basis of this, it can therefore be argued that the process of grieving in infertility is completely different to that of other losses, because the recollections and memories of the lost person are an essential part of resolving grief (Cudmore, 2005).

## **2.5 Summary**

Current literature analyses infertility within its social context, taking into consideration gender roles, couple's relationships and the effect of ART in shaping the experience of individuals with difficulty conceiving. The bulk of studies conducted so far tend to focus mainly on women's reactions to infertility, without an examination of how the

male partner is reacting to the same situation, or whether one partner's experience is affecting the other partner.

From available studies to date we know that women generally have more negative experiences with infertility than infertile men in most of the dimensions, such as lower levels of self-esteem and physical health, and higher levels of depression, stress, anxiety, stigma, and shame (Greil et al., 2010, Ying et al., 2015). The inconsistencies in some of the findings could be attributed to the study samples or the instruments used to measure the same dimensions. The gender differences in distress reported in these studies may have been influenced by gender stereotyping, as women tend to report more distress than men. In spite of this, the vast majority of the studies show that women are affected more by infertility. Cultural and social norms that emphasize the importance of childbearing as a woman's role might explain the gender differences in stress. Women usually feel more responsible for infertility than men (Loke et al., 2012).

A few studies available indicate that when the cause of infertility is attributed to the male, the affected male often feels a higher level of shame, guilt, anger, isolation, and personal failure. In addition, the profound shame, stigma, and assault on masculinity can be so devastating for men that they are too mortified to ask for help (Diamond, 1999, Inhorn, 2003, Hinton and Miller, 2013, Mikkelsen et al., 2013).

Despite a vast number of studies in the current literature examining the effects of infertility on individuals, relatively few studies that have examined the man as their unit of analysis. The above literature review therefore highlights the fact that there are still significant gaps in our knowledge concerning the experience of men diagnosed with infertility. It also highlights the need for future studies to take into account the cause of the infertility, and to also consider the positive experiences of infertile people. There is therefore a need of more qualitative studies that address the specific perspective of men diagnosed with infertility. Through this study I aimed to better understand how men approach the diagnosis of infertility, and azoospermia in particular, and I hope that in the light of the knowledge acquired, it will be possible to provide better information and support to such men and their partners seeking fertility treatment.

## **Chapter 3. Methodology**

This chapter provides a description of the methodology used, and justification and appropriateness for a qualitative research approach for this study. Ethical approval, research management, confidentiality issues and informed consent are also discussed here.

The method of data collection and generation involved qualitative interviews with individual men, in some cases accompanied by their female partners. The approach taken in analysing the data involved the practices and processes associated with thematic analysis and grounded theory (Glaser, 1967, Corbin, 2008).

### **3.1 Social science research**

To better understand the rationale behind the choice of methods used in this study, it is important to have an understanding of the range of social research philosophies and how they differ in the way they achieve their goals.

Two main epistemological philosophies inform social science research: positivism and naturalism (Denzin and Lincoln, 2013). Positivism argues that there is only one correct version of social reality which is directly discoverable and that can therefore be measured using standardised instruments, which often, though not always, aim for quantitative data (Rubin and Rubin, 2012). It supports the idea that objective accounts of the real world can be given using methods of the natural sciences to conduct social research, because human behaviour is governed by law-like regularities (Denzin and Lincoln, 2013). Positivists use techniques and tools that aim to reveal these regularities through standardised measures, arguing that this in turn enhances claims to representativeness, validity and generalisability. Naturalism on the other hand stresses the importance of interpretation as well as observation in understanding the social world and social interaction. Claims to knowledge are based on understanding and reflecting on social observation (Rubin and Rubin, 2012). Knowledge therefore exceeds basic empirical enquiry, since meaning is contextual and interpreted. Naturalists prefer using research tools that maximise the researcher's ability to access multiple definitions and interpretations of the ongoing social world and which reproduce the situated meaning construction practices that enable that social world to continue being reproduced. This can entail using techniques of open-ended questioning and observations, to access actors' discursive practices. Within the naturalist paradigm, one school, the interpretive

constructionists, put emphasis and value on human interpretation in building or 'constructing' their understanding of the social world (Rubin and Rubin, 2012).

### **3.1.1 The aims of qualitative research**

The aim of qualitative research in general is directed at providing an in-depth and acknowledged understanding of the social world, by learning about people's circumstances, their experiences, perspectives and histories (Ritchie, 2014). It is often described as an interpretative approach concerned with exploring phenomena 'from the interior', taking the perspective and accounts of research participants as a starting point (Flick, 2009). Denzin and Lincoln (2013) quotes:

*'Qualitative researchers study things in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings people bring to them' (p. 7)*

Qualitative research is still growing and is becoming more differentiated in its methodological approaches (Yilmaz, 2013). Although originally qualitative methods were used in research concerned with disciplines such as anthropology and sociology (Denzin and Lincoln, 2013), there has been widening of interest in the use of qualitative methods in other disciplines, including health sciences. The aim of qualitative research in the context of healthcare is to capture the interpretation of phenomena as experienced, and understood, by patients.

The epistemological underpinnings of qualitative research are concerned with the ways in which knowledge is best acquired, the relationship between the investigator and the participants, and the issues relating to what it means to accept particular claims as being 'true' (Ritchie, 2014). Two views exist with regards to how knowledge is acquired through qualitative research. One view is based on the 'inductive' approach, which looks for generalised patterns and associations derived from particular observations of the world. A different view is that knowledge is acquired through a 'deductive' approach whereby pre-stated hypotheses are tested against observations. Although qualitative research is often viewed as a predominately inductive paradigm, some authors argue that there is overlap between the two approaches (Blaikie, 2007), with both deduction and induction being involved at different stages of the qualitative research process. Blaikie, (2007) argues that when 'inductive' researchers generate and interpret their data, they have been influenced by assumptions deductively derived from previous knowledge in their field.

Similarly, deductive researchers trying to test a hypothesis will have drawn from a body of theory, which has been inductively derived from prior observation.

Another epistemological issue that concerns the interpretation of research findings that naturalist researchers are concerned with, is the role of the researcher's 'values, history and interests' as well as the relationship between the researcher and the participants, in the production of knowledge (Koch and Harrington, 1998). They argue that positivist researchers neglect this question to the detriment of their analyses and its usefulness to the practical world. This leads to the question however of how researchers deal with the tension between the supposed 'objectivity' that claims to knowledge require and their own 'subjectivity'. One model proposes that the researcher can be objective in their approach and the research findings are therefore seen as independent and as unaffected by the values of the researcher. Others believe that 'value-free' approaches are not possible because the relationship between social phenomena and the researcher cannot be neutral (Ritchie, 2014). Therefore, they argue that researchers cannot produce an objective account. As an interim approach, some researchers propose an alternative position of 'empathic neutrality', a middle ground position between becoming too involved, which can cloud judgment, and remaining too distant, which can reduce understanding (Gringeri et al., 2013). This approach recognises that research cannot be 'value free' but advocates an approach that minimizes investigator manipulation by trying to make their assumptions, biases and values transparent, while trying to be neutral and non-judgemental as far as possible. Naturalist or interpretivist researchers argue that these are epistemological challenges for all knowledge claims but that these questions are ignored by positivist researchers. However, these questions explain why 'qualitative' researchers emphasize the importance of personal reflection or 'reflexivity'; this is regarded as an important intrinsic feature of qualitative research that assist the researcher to determine the likelihood of bias and makes them aware of their relationship to their work (Ritchie, 2014, Gringeri et al., 2013).

A third epistemological issue that concerns all research, but qualitative in particular, is how to determine whether findings are valid or 'true'. It has been proposed that the intersubjective or coherence theory of truth is most appropriate (Richie et al., 2013). This is in contrast to the positivist correspondence theory of truth, in which findings are said to correspond with external reality, outside of actual experience of that reality. According to the coherence theory, an account is true and representative of

social reality if it is supported and 'coheres' with plausible accounts of 'what is going on'. One measure of plausibility is that an account coheres with other accounts and interpretations (Richie et al., 2013). Under the naturalist-constructionist paradigm of qualitative research, the fact that everyday actors, as well as researchers might reach different conclusions about 'what is going on' is not considered problematic, as long as the grounds for any plausible account are systematically warranted by reference to actors' situated accounts, since meaning is contextual and interpreted. With this approach, contradiction is intriguing; naturalist-constructionists would say that each participant could be speaking the truth as they see it; the researcher's task is to find the range of possible plausible accounts in any particular context (and what would constitute an implausible account in that context) and to identify the discursive practices that make alternative plausible accounts possible (Rubin and Rubin, 2012).

### **3.1.2 *Qualitative research designs and data collection techniques***

As discussed above, qualitative research is largely associated with the naturalistic perspective and interpretive understanding of human experience. It aims to describe and understand a phenomenon studied by capturing and communicating participants' experiences in their own words through interview and observation. It puts emphasis on the examination of the context that influences people's actions or interactions and the meaning that people ascribe to their experiences (Denzin and Lincoln, 2013). The phenomenon of interest unfolds naturally in that it has no predetermined course established by and for the researcher such as would occur in a laboratory or other controlled setting. The researcher's task is to provide the opportunity for everyday actors to elucidate how they make sense of the world around them and their experiences, for example through interviews with open-ended questions. That is why qualitative research requires an in-depth study of people's lives or the issues in their natural settings without resorting to standardised, pre-determined categories of analysis (Silverman, 2006).

Purposeful sampling plays a key role in qualitative research. Irrespective of the kind of unit of analysis, the main aim of purposeful sampling is to select and study a small number of people or unique 'cases' whose study produces a wealth of detailed information and an in-depth understanding of the people and situations studied. This sampling procedure limits the ability to generalise research findings to other settings or situations (Denzin and Lincoln, 2013, Patton, 2002, Wolcott, 1994). Qualitative

research is judged more on its ability to uncover new themes and new explanations, rather than on its generalisability (Rubin and Rubin, 2012).

Qualitative research uses a non-standardised, adaptable approach of data generation such as participant observation, semi-structured and in-depth interviews or focus groups. The data are usually in textual, sometimes graphical or pictorial form. Qualitative researchers disseminate their findings in a first-person narrative with a combination of *etic* (outsider or the researcher's) and *emic* (insider or the participants') perspectives (Denzin and Lincoln, 2013, Miles and Huberman, 1994). Open-ended responses allow the researcher to understand and present the findings as they are seen and experienced by the participants without predetermining those standpoints. Direct quotations document the participants' discursive practices and thereby display their depth of feelings, experiences, thoughts about what is happening, and meaning at a personal level. Hence, qualitative findings are far longer, more detailed and variable in content as compared to quantitative ones.

A key feature of qualitative research is that it is hypothesis-generating and inductive. Through open-ended questions it addresses the more in-depth 'why' and 'how' questions, as well as the 'what', 'whether' and 'who' rather than the more shallow 'how many', because it can directly ask those involved for their reasoning, rather than infer associations. Progressive focussing is used in qualitative research, a process of inquiry that involves a gradual clarification and sometimes transformation or re-formulation of the initial research question. The need for progressive focusing reflects the fact that qualitative research is governed by an 'inductive' or 'discovery' orientation, rather than by a conception of inquiry which requires fixed hypotheses to be set up for testing at the start of the process. In the process of qualitative data analysis and interpretation, new hypotheses and 'themes' often emerge from the data, in addition to the ones aimed to be explored at the outset (Silverman, 2006, Corbin and Strauss, 2008, Pope, 2000). Themes or categories are defined as higher-level concepts or summary statements, under which lower-level concepts are grouped according to shared properties (Corbin, 2008).

### **3.2 Project design**

My central research question was:

*'What is the experience and impact of the diagnosis of azoospermia on men attending a fertility clinic?'*

As discussed earlier in the literature review (Chapter 2), the impact that the diagnosis of infertility has on men is an underexplored area. It was therefore necessary to design a study that could provide a deeper understanding of, and knowledge, about this issue. The best method to answer this question therefore was a qualitative approach that would allow participants to describe the meanings attached to their lived experiences with regards to the diagnosis and treatment of their own infertility. This study was broadly influenced by the ideas and approaches of grounded theory (Glaser, 1967, Corbin and Strauss, 1990), that aims to describe social processes or actions through analysis of data from participants who have experienced them (Corbin and Strauss, 1990). The research design for the study was a qualitative semi-structured interview inquiry, because this method seeks the in-depth exploration of how men respond to, and feel about the diagnosis of their own infertility. A qualitative method was appropriate because qualitative interviews provide in-depth exploration of a question through extensive data collection, and give insight into the participants' understanding of the meaning of lived experiences (Silverman, 2013). They are conversational in nature and allow exploration of how the question under study is perceived and described by the participant in their own words (Osborne, 2011).

### **3.3 Research governance**

#### **3.3.1 *Ethical approval and consent***

Approval to conduct the study was obtained from the North East National Research Ethics Service Committee in Sunderland (REC reference 13/NE/0159, IRAS project ID 118390). All participants received a written (see information leaflet, Appendix A) and spoken description of the study, and gave written consent (see consent form, Appendix B) to participate in a face-to-face interview that was audio recorded. All participants were informed that their participation was voluntary and that they could withdraw from the study without consequence at any time.

#### **3.3.2 *Confidentiality and support***

All data remained confidential and participants were assured of this. Personal information was secured through data storage on a password-protected NHS computer. No identifiable data were removed from the NHS facility. Anonymity was protected by using a coding system (that could be linked back to their personal

details if necessary) that protected their identity during data analysis. Audio recordings, interview transcripts, and all other project related documents were kept in a locked filing cabinet for security.

Participants were made aware that their involvement in the study would not jeopardize their clinical care in any way. All participants had 24-hour access to a healthcare professional, specialist in fertility, through a telephone number. This would allow them to discuss further worries, emotional upset or disturbance that could potentially be triggered by the interview. All patients also had access to professional counselling provided through the Newcastle Fertility Centre. The information leaflet (Appendix A) contained links to organisations that could offer further support if needed.

### **3.3.3 *Research management***

The study received management permission (R&D approval, ref. 6530) from Newcastle upon Tyne Hospitals NHS Foundation Trust, in accordance with NHS research governance guidelines, and was adopted on the National Institute for Health Research portfolio (CLRN ID 118390). Data were handled in accordance with the Caldicott data protection guidelines.

### **3.3.4 *Funding***

Funding for this research came from the Newcastle Fertility Centre Research Fund.

## **3.4 *Sampling***

A purposeful sample technique was used to identify men (some together with their partners) to participate in the study. Men suffering from primary infertility for more than a year and over the age of 23 were included. Men who had been fathers in the past and men who had had a vasectomy were excluded from the study, as the aim was to explore the experiences of men who were coping with primary, involuntary infertility. Azoospermia was chosen because this is potentially the most difficult fertility problem to treat in men, requiring a sperm retrieval operation or the consideration of donor sperm use in most cases. They all had capacity to consent and were English speakers.

### **3.5 Recruitment of participants**

Potential participants were identified through the andrology clinic at Newcastle Fertility Centre. Participation was voluntary. Men were invited to participate by either writing to them (see invitation letter, Appendix C) or by providing information about the study during their visit at the male infertility clinic. A poster with information (Appendix D) was also displayed in the clinic waiting area, so that men could come forward to participate if they wish. I aimed to interview men who were at the stage of considering treatment options, have had either successful or unsuccessful surgical sperm recovery, and also men who decided not to undergo surgical sperm retrieval. This was because I wanted to explore whether the experiences of men depended on the success of their treatment.

The first 15 men that responded and agreed to participate were chosen to be interviewed in this study, on the grounds that they all fulfilled the criteria and there was no reason to assume that these first 15 men to agree would be any different from any other forthcoming men. Fifteen men were chosen because of the limited resources available for the study and because previous studies suggest that this number would be sufficient to reach initial thematic saturation, the point in data collection where no new relevant information is forthcoming from the interviews.

As discussed above, men received written information explaining in detail the purpose of this study (Appendix A), and were assured of confidentiality. The letter included a copy of the information leaflet, consent form and a stamped-addressed envelope to return their slip with final decision. They were asked to indicate on the slip whether they wished to take part or not (without giving a reason), and return the advice slip in the stamped-addressed envelope. Potential participants were reassured that deciding not to take part in the study would not affect their clinical care in any way. Reasons for the non-response or refusal to participate in the study could have been the following:

1. Reluctance to participate due to fear of breach of confidentiality. Some participants may have felt that participation in the study could compromise confidentiality, despite assurance of anonymity and confidentiality by the researcher.

2. Time and distance limitations. Some participants may have found it difficult to agree to participate in an interview, either because they could not find the time or due to living at considerable distance from the fertility centre.
3. Not feeling emotionally ready to participate, as they were already going through a stressful time. Participants may have found that taking part in an interview could trigger recollection of stressful life events they have experienced following the diagnosis and health care issues that may challenge their male identity, because of the recollection of their inability to reproduce.

### **3.6 Interview arrangements**

Respondents who agreed to participate were contacted by telephone. Interviews were arranged at a mutually convenient place and time. The aim was to interview men alone, but men who preferred to be interviewed with their partner present were given the opportunity to do so. When men and their partner participated in the interviews jointly, the main focus of the interview was still the experiences of the man.

The interviews were conducted between June 2013 and November 2013.

Participants were given the option for a convenient venue (including their homes) for the interviews. All interviews at Newcastle Fertility Centre were done in a quiet room, without distractions, so that participants felt comfortable, relaxed and uninhibited. Participant's own home environment also offered a relaxed atmosphere. Eleven interviews were conducted at Newcastle Fertility Centre and four at participant's home. With regards to socioeconomic status, the men interviewed represented different levels of the society. The majority were working or middle class and of Caucasian ethnicity. Occupation range included currently unemployed, warehouse attendants, civil servants and pharmaceutical chemists. None of the men in this study had children at the time they agreed to participate. All the men were either married or in a long-term relationship with their partners.

### **3.7 Data generation**

The interviewee received formal qualitative research training by attending two relevant training courses on qualitative interviewing techniques and on qualitative data analysis. This ensured good quality with regards to the conduct of interviews, the data collection and subsequent analysis.

### **3.7.1 Topic guide**

An aide memoir was formulated using concepts and themes suggested by the currently available literature on the topic. The guide was kept broad and was written with guidance from the researcher's supervisors and was approved by the ethics committee.

Interviewees were reminded of the aims of the project and were once again assured of anonymity and confidentiality at the beginning of each interview. Written consent was obtained and was re-confirmed on the day of the interview (Appendix B). The interviewee emphasised his role as a researcher and not as a doctor for the purpose of the interview. Once again, it was explained that what was said in the interview would stay confidential and that it would not affect their treatment in any way. Each interview was recorded using an Olympus DS-30 digital voice recorder, following appropriate consent from the interviewees.

Questions were asked in an open-ended approach and participants were allowed to give their own account of how they perceived the experience of going through investigation and treatment, and to emphasise the aspects of treatment that were important to them. A printed topic guide (Appendix D) was used from time to time to guide the interview. This was necessarily an interactive process, so that after the first 5 interviews, I had become so familiar with the content of the questions that I only needed to refer to a shorter version of the guide on a single A4 side of paper, developed as an aide memoir. This helped me to concentrate more on what the interviewees were saying and could then more effectively prompt interviewees for further clarification. I paid particular attention to new ideas that emerged through the interviews, which I then also addressed in subsequent interviews. My supervisors listened to interviews 1, 2 and then 6, 7 and provided feedback on technique and content. This ensured that the interviews were conducted appropriately and to the necessary standard. No new themes appeared to be emerging by the time of the last interview.

The recorded interviews were transferred as electronic files and saved onto a password-protected NHS computer. The interviews were transcribed by a professional transcriber and the transcripts were double-checked by the researcher for transcription errors and corrected where necessary. Each patient interviewed was assigned a code and any identifiable information, such as individual's age, ethnic background and occupation, was removed to protect the identity of the participants.

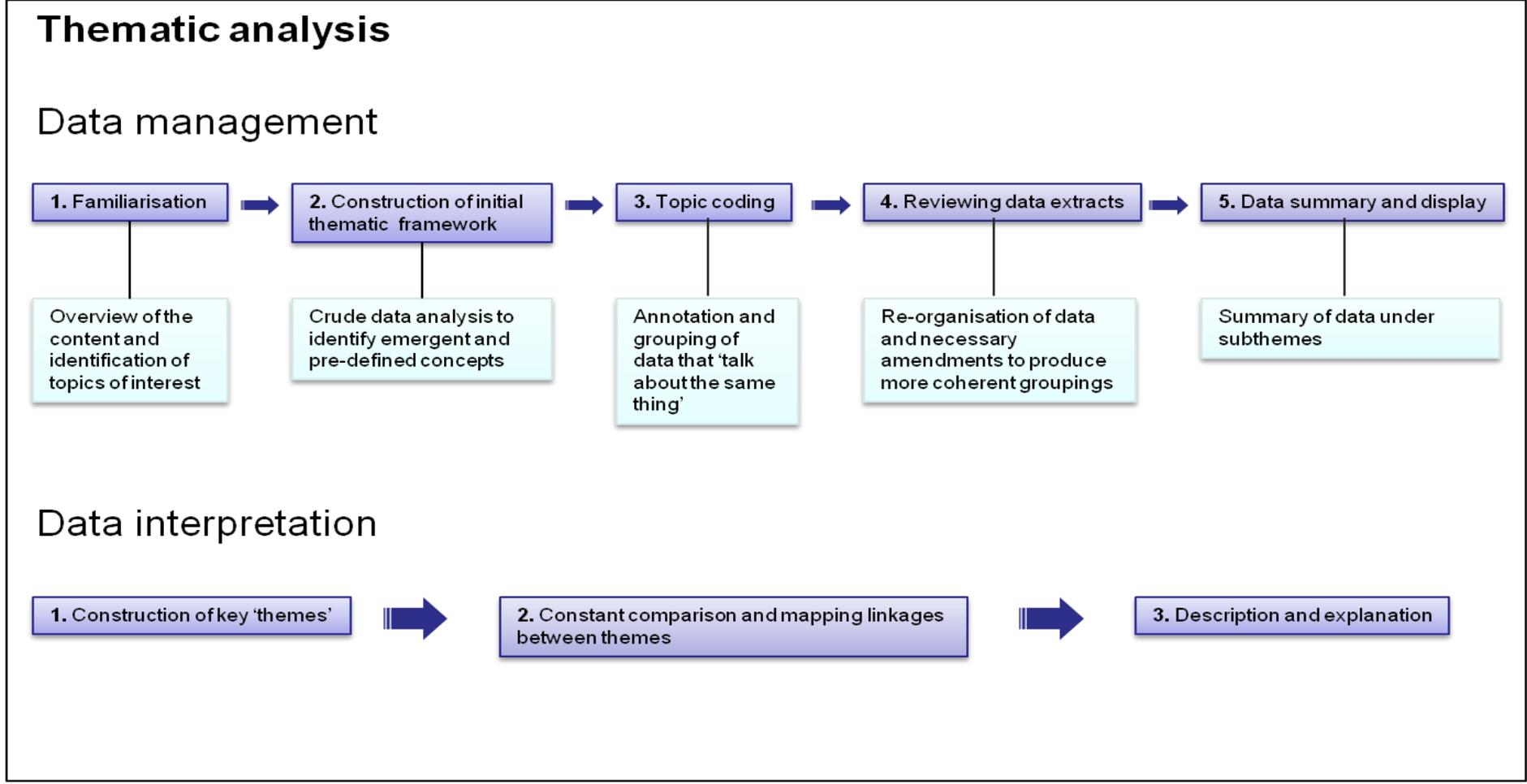
### **3.8 Data analysis**

Transcribed interviews were analysed by the researcher with the help of Nvivo software (Richards, 1994). A thematic analysis approach was used, the principles of which are summarised in Figure 1. This method of analysis involves discovering, interpreting and reporting patterns of meaning within data. Distinct threads of experience became apparent during the analysis of the interview transcripts.

Data analysis was both an exciting and challenging process. It was interesting to find out common themes emerging from the participants' experiences. It was challenging to narrow down themes as there was a vast amount of information and pages of transcripts to go through. The findings of this research will contribute to a better understanding of the way men experience the diagnosis of azoospermia, and help provide better care to such patients and couples that have not been well represented in the literature.

### **3.9 Summary**

The purpose of this study was to explore the experiences of men diagnosed with azoospermia. Male patients have rarely been the focus of infertility research, and therefore a qualitative interview approach was necessary in order to capture the whole spectrum of the experiences of infertile men, including the early stage of realizing the problem, seeking help, and going through investigation and treatment. Qualitative research provides a unique lens to achieve an in-depth understanding of the experiences of people, through learning about individual's circumstances and taking their perspectives into account. The research findings and data analysis from the interviews are presented in the following three chapters.



**Figure 1.**The analytic process of data analysis used for this study (Adapted from Ritchie, 2014)

## **Chapter 4. Men's initial concerns, reaction to the given diagnosis and further investigation**

### **4.1 Introduction to findings**

As discussed earlier, the aim of this study was to describe the lived experiences of men diagnosed with azoospermia. The data and evidence that evolved from the research are presented in the current and the following two chapters.

Data were organised under an initial set of 25 descriptive codes (Table 1), which were constructed from the initial analysis of the transcripts. This was used as a means of retrieving and categorising similarly-labelled chunks of information, a process known as cross-sectional analysis (Mason, 2002). Extra care was taken not to rely solely on the available literature as the major source for coding the interviews in order not to miss new insights in the data that are not available in the literature. At a later stage, the information was organised into five higher order, more refined categories (Silverman, 2006, Pope, 2000), aiming to address the overall research question : 1) Men's initial concerns and reaction to the given diagnosis, 2) Further investigation and search for a cause, 3) Disclosure of the diagnosis and means of coping, 4) Impact on men and their relationships, 5) Decisions about fertility treatment (see Table 2 and also chapters 4,5 and 6). This chapter explores the first two themes. Chapter 5 explores the themes relating to the disclosure of the diagnosis, means of coping and the impact on men's interpersonal relationships and everyday life. Chapter 6 describes the experience of having to make decisions to undergo a sperm retrieval operation and about the use of donor sperm.

Interviews were conducted between June 2013 and December 2013. The interviewees were promised anonymity and therefore names have been removed from quotes. Where appropriate, the original spoken language has been changed to corresponding grammatically correct English phrases. The designation at the end of each quote indicate the number of participant or partner and the specific paragraph in the transcribed text (i.e. INT-01: 14= Interviewee no.1, transcription paragraph 14, INT/P-07: 35= Interviewee no.7's partner, transcription paragraph 35). This allowed tracing the source of a quote in the original transcription.

Summaries are provided at the end of each chapter. An overall summary of the findings and comparison with the literature review data is provided in Chapter 7, together with suggestions and recommendations for further research.

**Table 1.** Construction of the initial thematic framework consisted of 25 subthemes.

1. Visit at fertility centre
2. Support seeking
3. Support seeking-partner
4. Semen analysis
5. Reaction to diagnosis
6. Reaction to diagnosis-partner
7. Physical examination
8. Past experiences
9. Operation- outcome
10. Operation- decision about
11. Knowing others with the same problem
12. Internet sources-forums
13. Initial concerns
14. Impact on self
15. Impact on relationship-friends
16. General comments
17. Further investigation-treatment
18. Explanation
19. Donor decision
20. Donor decision-partner
21. Donor decision-involvement of others
22. Disclosure of information
23. Coping mechanisms
24. Consultation without partner
25. Clinic support-counselling

**Table 2.** The five broad categories of emergent themes.

1. Men's initial concerns and reaction to the given diagnosis
2. Further investigation and search for a cause
3. Disclosure of the diagnosis and means of coping
4. Impact on men and their relationships
5. Decisions about fertility treatment

## **4.2 The interviews**

All men and their partners were very open and forthcoming to share their experiences during the interview process. All participants built up good rapport and opened up to the interviewer during the interviews. They provided detailed information about their reaction to the diagnosis and how it affected them emotionally and in their everyday lives.

Men said that they found speaking about their experiences very useful. One of the participants said that it was helpful for him to talk about his experiences because he could express himself and 'let it all out.' All men said that they were willing to participate in research because they were appreciative of the fact that someone was taking the time to conduct such interviews in order to learn more about the topic and help other men and couples in the future.

## **4.3 Initial infertility concerns and reaction to the given diagnosis**

This section represents an interpretation of men's experiences with regards to the first theme 'Initial concerns and reaction to the given diagnosis'. In particular, it describes the initial concerns that led men and their partners seek fertility investigation. It also explores issues with regards to the explanation they received from their GP and the reactions of the men when receiving the diagnosis of azoospermia.

Analysis of the interviews aimed at answering the following questions:

1. What concerns did men have initially that made them realise there might be a fertility problem requiring further investigation?
2. What was their initial reaction to the diagnosis?

3. Were men satisfied with the initial consultation and explanation provided by their primary care professionals?

At the time of the interview, three men out of fifteen were in the process of being further investigated in the fertility centre and had not yet decided whether to have a sperm retrieval operation. Eleven men had a sperm retrieval operation, either successful in retrieving sperm suitable for treatment, or not. One man was being managed conservatively following cessation of anabolic steroid use.

#### **4.3.1 Concerns leading to infertility investigation**

Before starting to look into how the men felt about being told they were azoospermic, it was important to understand how couples reached the point of seeking fertility investigation. The following section focuses on what went through men's (and their partner's) minds and how they reached the point of diagnosis.

##### **4.3.1.1 Reasons for seeking help**

The majority of men learned about the diagnosis following a period of trying to conceive with their partners without success. These men explained that they realised gradually of the possibility that there might be a fertility problem. A delay in conception between one to two years was the primary reason for seeking further investigation for the majority of couples.

Two of the men, who were trying to conceive for variable periods of time, commented:

*'...well we stopped using protection...it was two year into our relationship and it'd been like a year and a half, coming up two years when obviously nothing was happening' (INT-03:12).*

*'We were aware that we weren't getting any younger and we hadn't been using any contraception for up to eight years.... but we'd actually been trying actively for eighteen months....I think it was over, just over a year when I first asked the GP if there is anything we could start checking into...so that's when I had my first sperm test' (INT-07:15).*

Referral for further investigation for one man was triggered by finding out that his brother had been diagnosed with a genetic condition that causes male infertility. His brother suggested that he also got tested for this condition, and he decided to do so. The couple were not trying to actively conceive at the time and the man said:

*'My brother was trying to basically conceive a family and it was identified that he had an issue with the development of his reproductive organs, and they said at the time that was hereditary and for me to go and get checked out' (INT-08:19).*

Some men explained that they were suspicious about the possibility of a fertility problem, because of previous experiences with ex-partners which led them to believe there could be a fertility problem. One man said that he suspected he had a problem, because he had never impregnated any ex-girlfriend that he was sexually intimate with. Another man stated that he similarly suspected that something might be wrong, because when he split up with his girlfriend at the time, soon after he found out that she was pregnant with her new partner. The men said:

*'I thought it was me. I don't know, it was just something in my mind that thought 'it's, it's me'. I mean, my previous partner I was with before my wife now, we weren't using any protection then, and she never fell pregnant. Then obviously we split up, got with me new wife and then she fell pregnant (with her new partner). So that made me think, well if we didn't (fall pregnant) and she has now, then obviously it could be me' (INT-03:32).*

*'The reason I thought that, is because, when I was younger I had quite a lot of girlfriends, a lot of un-protected sex, but never managed to get anybody pregnant. So, I used to live with a girl called xxxx, and I lived with her for a good while, and then we split up...and shortly after she met somebody and got pregnant. So that sort of think made me wonder whether it could be something with me' (INT-11:43).*

#### **4.3.1.2 Lack of awareness about male factor infertility**

Several men said that he always assumed infertility to be 'a woman's fault' and never expected that such problem could occur in men. Ten out of fifteen men assumed that the problem would lie with their female partner, who often initiated the search for solutions to couple's delay in conception. The following participant said:

*'...I didn't think it was me to be perfectly fair, but I thought the first thing we can do is go and see a doctor... but up until then we just thought we were missing the dates...' (INT-10: 15).*

This view was also supported by another man, who assumed that the problem was with his wife because she had a family history of polycystic ovarian syndrome, an endocrine condition that can cause subfertility in women. He assumed that there were no fertility difficulties running on his side of the family. He said that because his

brother and close relative were already capable of producing children, it didn't cross his mind that the problem could lie with him. He said:

*'I assumed it was all my wife because of her family history; her sister's got polycystic ovaries, her mother's got polycystic ovaries... On my side, my father has had me and my brother, my uncles have all got a hundred loads of children...my brother on the sperm count's fine so obviously I didn't think it was nothing to do with me...I automatically assumed that I would be like the rest of my family, and I have plenty of sperm to produce children...'* (INT-14: 27).

Another participant commented:

*'...up until that point in my life I had never once thought that there was a problem because I, to my knowledge, experienced the potential of possibly getting a girlfriend pregnant and there was a big scare at the time and all that. So, I never once thought that I had any issues'* (INT-08: 19).

#### **4.3.1.3      *Initiation of fertility investigation***

The female partner took the initiative to initiate the infertility investigations in the majority of couples. There was reluctance from men to seek help, and this could partly be due to the lack of awareness about male factor infertility. One participant recalled becoming concerned about his fertility after his wife pointed out to him that infertility can occur in both men and women. When pregnancy failed to take place after a few months of trying to conceive, one man said that it was his wife's GP that referred him to have a semen analysis test, which proved to be abnormal:

*'...so she (my wife) went to her doctors to see about whatever test she could do to find out, and so that it was my wife's doctor that referred me to the hospital to have a sperm test and of course that -sperm test came out negative'* (INT-11: 19).

#### **4.3.1.4      *Reluctance to seek help***

Even when they anticipated a potential infertility issue, some couples and the male partner in particular, expressed reluctance to seek help immediately. Those couples went through an avoidance or denial phase before accepting the fact that there might be a problem. One interviewee described how the delay in conception made them reluctant to seek further help, after they gradually started to realise that there could be a problem with one or both of them:

*'Most of the time I think I was just trying to ignore it and hope something, you know, happened (i.e. pregnancy). Erm, so, but a little bit of putting my head in the sand, kind of thing. But obviously she was getting more and more upset, that's when we yeah, we went to it (to see the GP)' (INT-02:31).*

And he continued:

*'...you go to the doctors and that's the, you know the, taking that first step is quite difficult, because you, you then, you're then accepting that there is something wrong with one of us, or both of us' (INT-02:19).*

### **4.3.2 Reaction to the given infertility diagnosis**

Participants experienced a number of different emotions during the process of discovering their infertility diagnosis. Thirteen out of fifteen participants recalled experiencing strong emotions upon discovering their infertility, with eight also experiencing feelings of self-blame and failure. Ten of the men stated that they were in a state of disbelief and denial after the initial diagnosis. Several of them stated that they did not expect such condition of completely zero sperm count to exist in men, highlighting once again the lack of awareness in male infertility.

#### **4.3.2.1 Disbelief and denial**

Disbelief and denial were amongst the most commonly expressed behaviours to the given diagnosis of azoospermia. Men found it difficult to believe that there was a complete lack of sperm in their semen. The majority questioned the accuracy of their test results and expressed doubts following the initial semen analysis test. Men said that they found it surprising because they had always assumed that infertility was 'the woman's fault' and also because it was not associated with any alteration in their sexual function or any other symptom. Because of their initial doubt about the diagnosis, the men requested a repeat semen analysis test on two or more occasions in order to confirm the diagnosis.

Semen analysis tests are usually repeated once, if abnormal, in order to confirm that the result is not spurious. The majority of men had more than two sperm tests arranged, with one man admitting that it took three semen analysis tests before he realized that there was a serious problem:

*'I knew I was going to get my results and I was thinking they are just going to come back and say it is a low sperm count it is not going to be that bad of a problem to be honest. In my mind at that time I didn't even think zero even was a possibility... think I really had three tests before it kind of sank in a little bit, before I realised there was a bit of a problem'* (INT-01:21).

Similar doubts were expressed by another participant who was using anabolic steroids for fitness training. He said:

*'I didn't expect (the anabolic) steroids to kill it completely to where it was, it was zero, that was a massive shock when, when I found that out'* (INT-10:31).

One man described how he was in a state of denial, pretending to believe that the first two semen analysis tests that he did were wrong:

*'...the second sample which I did was at a different hospital...I didn't believe it initially, at that point it wasn't the end, you know, it wasn't a definite diagnosis, it wasn't, you know, (so I said) let's, let's try this again'* (INT-07:25).

#### **4.3.2.2 Emotional response**

The most commonly expressed emotions were shock, devastation and sadness. Some men also experienced physical symptoms and depression. These are reflected in the following quotes:

*'It was a real shock to the system and I didn't know who to tell...The last few months (following the diagnosis) I've had a sweat on my face and it took me a little while to cheer up a little bit, maybe the sunshine is helping, I don't know, but we'll see what happens in the near future, hopefully it'll not be too long (until the operation)'* (INT-01:43, 107).

*'...it was the second letter I got back from the doctors, that was probably the worst moment because I got a little letter which just said again the second time 'they've shown no sperm in the semen'. If you want to see the doctor, make an appointment'. And that was when, I think the only time I really got physical response from hearing that, you know, and having that letter, that's it, it's me. You know, 'there is something wrong with me' and that was the worst point...'* (INT-02: 21).

Another man explained how he felt confused after receiving the diagnosis, not knowing initially what the implications were. He remembered feeling 'drained' and 'depressed':

*'Well, once I've done the sample and we got the letter, I mean she (my wife) broke into tears and I felt like doing the same..., but I couldn't...I really didn't know what to make of it to be quite honest, 'my head was just all over the place'. I just felt drained; my personality just changed, you know, 'it was a kick in the nuts basically'. It was heartbreaking to find out that there was something wrong... But then after a day or so we sort of sat down and spoke about things and I perked myself up a bit...'* (INT-03: 34, 47, 51).

Another man, who was very surprised by the result, commented:

*'...So at this point I had now done three tests and all came back with exactly the same results. And, the second time to go and get the results from North Durham I felt absolutely terrible'* (INT-04: 15).

One of the participants remembered being told by his GP about the semen analysis result, and described how disappointed he and his wife felt when they found out about the lack of prospect to be able to reproduce naturally. He said:

*'We got told (by the GP) that there was no sperm in the semen, which was like a major blow... I was gutted really because I wanted it just to be natural and obviously it wasn't meant to be that way...'* (INT-03:37).

He then continued to explain how upset he felt about the diagnosis and to describe the communication difficulty he experienced with his wife after he found out about the diagnosis:

*'...I remember coming home from that first appointment from North Durham and I was in the car and I was quite upset by the whole situation and my wife was naturally upset as well, which I think ended up in more of a feedback loop cos I kept getting more upset cos she was getting more upset.... and I found it very difficult to talk to her as easily about it but I did try and force myself to talk to her because I felt that she needed that, although we, I'm quite a, I don't need to dwell on the, on the fact to deal with, to deal with it but she needed to talk about it so I tried to force myself to discuss the situation with her...'* (INT-04:17).

Participant 5 described how devastated he felt at the point of finding out the diagnosis and possible implications. He stated:

*'...I was devastated because there's never been, as far as I'm aware, there's never been a problem in the family...it was just denial really, you don't, you don't think it can happen to you... it was devastating to know that you're not going to have your own kids' (INT-05: 27,61).*

Participant 8 said that he took the diagnosis 'quite hard' because it shattered his dream to have children naturally and be a biological father, what he believed to be 'the ultimate life goal' for a man. He recalled feeling as if it was 'the end of the world' and that he felt withdrawn and didn't want to talk to anyone about it. He also reported that it took him several years after the diagnosis to come to terms with it. His exact comments were:

*'At the time I felt as if, how can I put it, you feel as if, it's sort of 'the end of your world'. You know, to think yourself obviously you're a man and that's basically the ultimate goal is, in life, as far as I am concerned is, is to replicate what your parents have done. You want to be a father; you want to be a dad. Not at that particular time, but going forward, and I, 'I took it quite hard', I would say 'I didn't really want to talk about it'. Er, and it's only probably the last three or four years that, you know, that I've sort of come to terms with it really' (INT-08: 39).*

Participant 10 explained how embarrassed and upset he felt to find out that the steroids he was taking were responsible for his azoospermia and his fear that his marriage could end, because of that:

*'It was embarrassing. It wasn't something to laugh about, it was very serious, it was when I got the letters and when I got the results it was, it was upsetting. I thought my marriage was going to be over, because all she's ever wanted is kids' (INT-10: 71).*

And he continued:

*'It's a big thing to be told your manhood's nothing, you know...all you want is a baby and your wife's going on about a baby and she's blaming herself. And then when you find out it's you, and what you've been doing, what you've been taking, the things (steroids) that you think can't harm you, that make you stronger and fitter, you don't expect them to have such an impact on you... so I felt embarrassed, upset, and I felt like a let-down to my wife, because obviously I knew what she wanted and it was me stopping her from having what she wanted, by being silly, in some respects' (INT-10:41).*

One man confessed being emotional when he was told about the diagnosis, and he went on to explain how the idea of visiting the fertility centre gave him hope that there was a possible solution to his problem. He stated:

*'...well I'll be honest with you, I'm quite emotional so I was a bit upset about it that obviously in hindsight that a couldn't make me wife pregnant, have our own children and initially I thought, well there must be something that could be done with medicine as it is these days...We were both upset for a while until we came in here (the fertility centre) again and then we were told the options...'* (INT-14: 13).

Participant 15 explained how he dreamt of raising a small family and believed that having children would not only allow him to pass on his values and beliefs to the next generation, but would also serve as a motivation for him to live and be a better person. Hence, he explained how depressed and 'psychologically hurt' he felt by the news of his infertility:

*'...well pretty gutted as you can imagine. I mean [coughs]...that are probably the hardest hitting information that I've received out of the process. You automatically just assume well that's the end of the line really. For me at least it means you're kind of start thinking why, I'm never going to have like a child of my own and all this and obviously it's quite, well it's very depressing, very hard to cope with... it does take a lot of time to kind of get used to it...there's literally no positives to take away. I mean it's literally all devastating information'* (INT-15 57).

The diagnosis of infertility was not a surprise to all the men interviewed. Two men had a suspicion that there might be a problem, because of fertility issues that they experienced with previous partners. These two men explained that, because of their prior suspicion, they did not experience the initial shock that others might have felt. This did not however stop them feeling 'disappointed' and 'devastated'.

Participant 11 felt disappointed and expressed a feeling of failure because he could not fulfil his family obligation to make his wife pregnant. He said:

*'...and especially considering the time me and my wife had been trying to conceive as well, it didn't sort of hit me as a brick wall, it wasn't shocking news to me, if you will, it was more of a confirmation of what I was suspecting from before...I didn't go into any state a shock or have to go away anywhere to sort of like sit and think about the news I'd received or anything like that. It was pretty much the news I was*

*expecting. But it doesn't stop me being disappointed that I couldn't get my wife pregnant... because I think if anybody's gonna be a nice mother, she'd be a brilliant mother...”(INT-11: 75).*

Similarly, another man explained that because of a history of a testicular problem (history of undescended testes), the diagnosis did not come as a surprise, but it did confirm one of his ‘worse nightmares’ and he felt devastated to find out:

*‘(I felt) devastated, obviously, but I had a funny feeling anyway, because of my past problem and that...so obviously I was devastated, don't get me wrong...it's one of my worst nightmares came true, if you know what ah mean...’ (INT-12: 57).*

Participant 7 explained that he was expecting confirmation of the diagnosis when he visited the fertility centre and that he wasn't shaken. He explained how the third semen sample done at the fertility centre confirmed the diagnosis of azoospermia and offered him a sense of closure:

*‘...it was an expectation in some ways because I had already had the two zero sperm counts, so in some ways it was not new news...it just confirmed the disappointment that I'd already felt’ (INT-07: 84).*

Participant 9, a man of African origin with strong Christian faith, explained how important it was for him and his wife to have a family with their biological children. He said that he knew couples that were child-free by choice, but when on to explain how important children were to him and his wife because of his cultural background. He commented on how ‘soul destroying’ it was to find out that he was not producing any sperm, and highlighted the cultural beliefs that made the acceptance of the diagnosis more difficult:

*‘...it was soul destroying in a way, it was because you don't expect anybody to tell you that this is the situation, you know, and being Africans as well, we are very family-oriented people...the culture I come from, we want, we always, we love children, we want children. In this part of the world, the Western world, there's some people that don't want children, not that they can't have children but they just don't want children because that is their choice. But where I come from it's a different ballgame, if you get married today, the following day they be asking where is your baby?’ (INT-09: 133).*

Participant 11 said that he found it frustrating that he didn't have control over the fact that he could not have children.

*'Previously in my life I've basically done what I wanted. If I wanted to do something I've done it, you know? I've made it my way to do it. Whereas this (the azoospermia) I can't do anything about. So that could be quite frustrating, because I can't do anything about it'* (INT-11:81).

### **4.3.3 Explanation of the diagnosis and referral to the fertility centre**

#### **4.3.3.1 Explanation of the diagnosis**

Receiving the diagnosis of azoospermia from their General Practitioner (GP) was central in all men's experiences. An important element that emerged from the interviews concerned the GPs' explanation of the men's health problem. Men perceived that their GPs lacked knowledge concerning male infertility and expressed the concern that on some occasions the diagnosis was given in a non-sensitive manner, with a lack of empathy.

More specifically, several men were concerned about the lack of knowledge in the subject by their GP. They felt that their doctor did not give them enough information or an adequate explanation about the possible reasons for their problem, or the fact that an identifiable cause may not be found.

One participant who felt that his GP was lacking knowledge about the condition commented:

*'...it was a young lad (the GP) who I spoke to and he didn't have a clue to be quite honest'* (INT-01: 17).

This view was expressed by the majority of participants, who reported a general feeling that their GPs lacked knowledge in male infertility. Their view is reflected in the following quotes:

*'...I had two zero sperm counts at this point... there was nothing explained further than, we will refer you to the specialists, to the experts. That was it...'* (INT-07: 25, 54).

*'...I went and gave some samples and came back and there wasn't really much of a discussion or anything, it was just that there was no sperm. That was it...'* (INT-08: 35).

*'She (the GP) couldn't give me no answers, no information, no nothing and I think going through the GP is the wrong way to go' (INT-10: 143).*

Some men were also critical of their GP's approach when giving them the diagnosis. One man expressed concern at the lack of empathy by their GP:

*'...(the GP said) 'You might as well just start looking for donors', and I just felt, it just felt terrible that at this point we hadn't even, repeated the test at the specialist clinic but I'm already getting told now to start thinking now there's probably pretty much no chance... Empathy was never even considered, it was, this is clinically, that's it...'* (INT-04: 17).

In light of the situation, the same participant highlighted the importance of addressing the lack of access to counselling at the initial stage of the diagnosis and while awaiting referral to the fertility centre:

*'...I had obviously been given bad news, I was anxious about the situation...There were no facilities for counselling or anything at that point...'* (INT-04: 17).

#### **4.3.3.2 Referral to the fertility centre for expert opinion**

Following the initial diagnosis of azoospermia, men were referred to the specialist fertility centre by their GP for further management. A number of men expressed concern about the lack of information they received with regards to what happens at the fertility centre, and some reported a delay in the referral to a specialist centre from the time of the initial semen analysis.

Participant 10 felt that his GP did not give him enough information about what was going to happen next, and what to expect from his referral for further investigation at the specialist centre. This is how the man put it:

*'...we went to see that doctor (the GP) who was very arrogant, didn't speak any English really, she just went, 'no sperm, I refer you', and that was all I got... and I burst into tears when she went, "No sperm". Erm, 'Refer you', that was it. I got no information about what was happening, what to expect, what we could, what I could do, it was, it wasn't good'* (INT-10: 143).

One man said that he was given the result of his sperm test over the phone. When asked what his GP's explanation was, the man said that his GP did not arrange a

follow up appointment to see him in person but instead he was referred straight to the fertility centre.

*'...we didn't actually go back (to see the GP). We were referred straight here' (INT-15: 26).*

One participant commented on how nice and sensitive the GP was when giving the diagnosis, but felt that he was given too much information too early during the initial consultation. He said:

*'...she (the GP) was quite sensitive to the fact that this could have implications...the thing I found strange about it was that she started talking about things like adoption...but to me it was far too early in the process to start thinking about things like that, but I think she was just a naturally sort of talkative person and she was just chatting about various options and things...she was sensitive and very nice about it...'* (INT-07: 23).

Participant 4 expressed concerns about the significant delay in his referral to the fertility centre and he described how anxious he felt after receiving the initial diagnosis, mainly because there was nowhere to turn to for reliable information while awaiting his referral:

*'...I was distraught about the fact that it was so bad that I had obviously been given bad news, I was anxious about the situation... and then just to be left for nine weeks...and to be quite honest I don't think I hadn't rung up it could've been even longer'* (INT-04: 23).

#### **4.4 Referral to the fertility centre: expectations from the medical consultation**

Following referral to the fertility centre, the consultation itself played an important and central part in patients' experiences of their fertility problems. In the fertility centre setting, the medical consultation allows thorough clinical assessment by an expert in male infertility and the provision of information about possible causes for the azoospermia and available treatment options. Availability of professional counselling is readily available. This provides information to the couples and aids decision making with regards to treatment. Good communication skills are at the centre of achieving a satisfactory consultation.

During the interviews, participants described their experiences of visiting the fertility centre. It appeared that men and their partners saw the visit to the specialist clinic as an opportunity to get answers and real pragmatic help for their problem. Most

participants said that they felt reassured and confident visiting the centre and that their referral gave them a sense of hope about the future and helped them stay positive, despite knowing that the success rates for the treatment of azoospermia were very low.

#### **4.4.1 Visiting the fertility centre**

Participants saw their visit to the specialist centre in a positive way, and as a means of getting an explanation for their problem. They expected to discuss possible reasons for their problem and available treatment options in order to help them move forward.

One couple said that they were unaware that they could get further help and treatment for azoospermia from a specialist centre. The man appeared very relieved to find out that there was potential help from the specialist fertility centre. He said:

*'... just when my doctor (GP) told me (of the diagnosis), I thought that was it...that there wasn't really much help. But then, they referred us both here (the fertility centre)' (INT-01: 35).*

He then continued to describe how 'daunting' he found the experience when he first visited the fertility centre because he was not used to discussing personal issues openly:

*'... It was daunting first coming here and then I thought, after the first time I came, this is going to be quite a few appointments...we never really used to talk to people about this thing (trying to conceive)..'* (INT-01: 35).

Another participant explained that the referral to the specialist fertility centre for expert help gave him hope that his problem could be resolved. His comments were:

*'Well obviously it's a good thing to have people looking into things for you, we are no experts, we couldn't work this out ourselves, so it's nice to have this facility in our own area that we could come to and speak to experts and have further tests here'* (INT-07:58).

And he continued:

*'I am aware that a zero count is particularly bad, a small sperm count might have been more encouraging of course, but yes, I was hopeful that because I was coming to the experts that something might be found, maybe a different result or with a some medication or treatment*

*we could reverse whatever the problem was...I was hopeful that it could've been resolved...'* (INT-07:78).

Participants 4 explained how confident and reassured they felt when visiting the fertility centre for expert advice:

*'I felt more confident coming here... and obviously the reputation of the Centre nationally and internationally was more of a comfort to me, that I knew that I was going somewhere specific'* (INT-04:21).

Participants 8 and 11 stated that they were prepared and looking forward to visiting the fertility centre, in order to find a final answer for their problem and find out what the treatment options were, in order to help them move forward.

*'I was prepared basically because the amount of time that had passed between my initial diagnosis of no sperm...I knew in my mind that it was the only route forward. So I was quite at ease about coming here. Happy to come and to move forward because, that's what, that's what I want to do'* (INT-08:77).

*'It didn't worry me as such. It was quite good actually to get to know once and for all, so it- I was quite happy to go there and do the test, you know, I was slightly disappointed that it turned out negative. But it wasn't totally unexpected for me'* (INT-11:53).

Participant 14 who was subsequently diagnosed with a genetic condition (Klinefelter syndrome), commented:

*'At first I was very nervous but now, it is second nature. I could walk in here (the fertility centre) no problem...in a sense I'm very grateful, I'm quite lucky that I come here, to be fair...because I still wouldn't know what was the matter and I'd be banging me head against the wall, why?'* (INT-14:165,167).

Participant 15 stated that he had mixed feelings about visiting the specialist centre. On one hand, he felt lucky that the facility of a specialist referral centre was available in his doorstep, and that he had easy access to a consultation with a specialist in order to seek an explanation and treatment for his problem. On the other hand he said that he would have preferred not to have to go through this experience. He explained:

*'I felt a bit mixed. I mean obviously I'd rather the situation was that we didn't have to come here, but the same time we were quite, quite lucky*

*in a way that we did have this (the specialist centre) on our doorstep, more or less. I didn't feel great (having to come here), but again it wasn't all negative really. At least I knew we would be getting the help we needed...we'd be going somewhere that did, that would be able to offer like help, and give us answers. It was good that we had access to this, but at the same time it would be better obviously if we didn't have to come here in the first place' (INT-15:33, 35).*

One study participant explained that the most difficult part of going through investigation and treatment was the uncertainty of not knowing how long the treatment was going to last and the uncertainty of whether it was going to work. He described how the couple's lives were pretty much 'on hold' because of waiting for follow-up appointments and worrying about the results of the investigations and the outcome of treatment. He said:

*'You're going through all these things...you've got weeks where nothing happens and your life is on hold and you're just waiting for the next appointment. It does seem like you stop start and stop start until the next thing. So it's difficult to get everything in your head, it's quite surreal. There's a lot of waiting and then your life is pretty much on hold because you can't plan, or it feels like you can't plan anything, you're just waiting for the next one (appointment) to get over that and again... and obviously because of the (low) chances involved it's like u know...you're you basically spend months expecting bad news. Basically that's how we, that's how we've been through it' (INT-02:75, 77).*

One couple described a not so positive experience with regards to their visit at the fertility centre. They felt that they were not given enough information about their treatment in a timely fashion in order to help them make informed decisions about their treatment:

*'I'm quite surprised on the basis that it's our fourth visit today, that it's only today that we've been given sufficient details about the costs involved let's say and you know, we've really had to sort of, ask a lot a questions about what happens next really... But at the same time everybody's been very helpful and very supportive and very sensitive if you like about the issue. So I've got no complaints at all, but we've had to push for the information that we need in order to take future decisions' (INT-07:128).*

#### **4.4.2 Information provision prior to visiting the fertility centre**

Some participants said that they did not receive adequate information prior to their visit at the fertility centre. As a consequence, they said that they felt 'nervous' about the visit to the fertility centre because of their limited knowledge with regards to reproductive health, uncertainty about what to expect and lack of familiarity in discussing very personal issues. Participant 10's description was as follows:

*'... (I felt) nervous. Very nervous because obviously, it's a big thing to be told your manhood's nothing, you know... I was really, we were really nervous because obviously we didn't know what to expect...but when we did go to the Centre, I mean, the staff were brilliant, they made you feel at ease and they didn't judge you, which was nice...'* (INT-10: 41, 57).

#### **4.4.3 Feeling not alone**

Two men explained how visiting the tertiary fertility centre made them realise that a number of other people, of different ages and backgrounds, were going through similar fertility problems. This made them feel less isolated, because they found out that there were other people 'out there' with similar problems.

*'Well, at that point (of finding out) it's quite isolated, you feel quite isolated, you feel quite alone, because I can speak to my partner, but you know, she is upset because she wants to have children and I'm the person who, who can't give her children...but coming to the centre was a good thing because it looks scientific, it looks like it's 'the business' as it were. So that was quite reassuring coming in and seeing other couples as well, so that was the first point where I felt I am not quite so isolated, not quite so on my own... so yeah, coming to the Centre of Life and to see everything that was set up here was a positive thing...'* (INT-02: 39).

Another participant said:

*'...but no I would say the Centre for Life is the best thing that could've happened for us, with the knowledge that we've gained from it...it sort of opened our eyes. We don't feel as nervous... everyone's in the same boat so you're sitting there wondering, I wonder what he's in for, wonder what she's there for, we are all there for the same reason, we didn't expect so many people to be in. So, we were quite shocked and on different ages of people as well, we expected older people, and there were people our age that were there, some younger'* (INT-10:57).

#### **4.4.4 Producing a semen sample for analysis**

Participants were asked to describe their experience of having to produce a semen sample for analysis. Not all participants produced the sample at the fertility centre's facilities. Some participants produced their semen sample at home and others explained that they had to use the hospital's male toilets. All men said that it was 'something they had to do', because there was no other way of finding out the diagnosis, and expressed some degree of embarrassment and discomfort at having to produce a semen sample under these circumstances.

#### **4.4.4.1 General thoughts about the semen sample production**

One participant described how his partner tried to put him at ease just before visiting the clinic to provide a semen sample for analysis. He said:

*'I was really quite nervous and my partner was actually winding me up all the way here...so we had a bit of a laugh and this kind of settled my nerves a little bit...I think she was trying to get me thinking about it I suppose, because I kept saying that I can't go and do it just standing there' (INT-01:37).*

And then, reflecting on his actual experience of producing the sample at the clinic he said:

*'Just doing that (trying to provide a semen sample), when I knew there's people next door it was really daunting ...and I thought I've got to do it, and when the time came I gave it a shot and just calmed myself trying not to sweat or anything. I was quite nervous and I think that affected my output so to speak, because I think if I had done it in the house, I would have done a little bit better... but I think me partner helped me a lot. It was not the most enjoyable thing to do but I will always remember it' (INT-01:37).*

Participant 12 described how he tried to see the funny side of it in order to relax:

*'I just saw the comedy side of it, we just had a laugh about it, basically. Having to go in with some porn mags and that it was, we just had a laugh about it, really, so I was fine, yeah' (INT-12: 42).*

Participant 7 explained how un-natural the whole experience of providing a sample was for him. He said:

*'It wasn't particularly pleasant in any way really...I mean a little room with a seat and a sink and a couple of magazines I remember in an envelope, it wasn't a great experience that but I just realised it needed*

*to be done and the sample was gonna be analysed immediately, so I can understand the erm the reasons for doing it. But no, that wasn't great' (INT-07: 62).*

Participant 6 said that he felt embarrassed having to do the sample in the clinic, but explained that he had no other choice:

*'I was OK with it. I felt a little bit embarrassed, but I think that's just natural isn't it, to be embarrassed. But, like I say, I just either do it or I can't really find out, it's gotta be done' (INT-05: 37).*

Participant 14, who attended his local hospital for his first semen analysis sample, explained how undignified he felt when he was asked to provide the sample in the hospital toilet:

*'...not the most dignified thing in the world to be fair, to be in a toilet with a pot, but because it was for a purpose I didn't think of anything else but for that purpose, to find out. Luckily for me there was nobody in the toilet at the time [laughs]. I did find it slightly degrading. Because it was for the purpose of science and to find out what was the matter, then I didn't think of it in any other way' (INT-14: 89).*

Participant 2 described how difficult he found the idea of providing a sample at the fertility centre initially, and as a result he produced his first sample at home and asked his wife to transport it to the hospital:

*'I couldn't do that (provide a sample) here (at the clinic) ...it was incredibly difficult. It was not so bad to do the sample at home and then I made my partner go in and hand it in at the desk' (INT-02:45).*

When questioned why he asked his partner to hand in the sample and he didn't do it himself, he said:

*'I've only ever been to hospital or the doctors once before, and that was with a sports injury. Having experience with hospitals is new, so it was that side of it. But the thought of going in with a little tube (containing the semen sample)...I know doctors do these things all the time and are aware of it and everything, but I'm not... so it's the idea of handing a sample over to somebody who knows what it is. I didn't want to face that bit, no'(INT-02: 57).*

After overcoming the initial difficulty of providing the semen sample at the clinic, he explained how unnatural the process of producing subsequent samples at the clinic felt:

*'There is two sides here, one is, you are making something medical out of something that's sexual, you can't just sit in there and sexualise it, so it's difficult. The second one is the room itself, it's a little room with a seat in it with a wipeable cover, you are in a corridor and you can hear people going past all the time, so getting an erection was very, very difficult... getting there, and then, the pressure builds...I couldn't be a porn star, put it that way (laughs)' (INT-02: 47).*

#### **4.4.4.2 Production room facilities**

Participants were asked to comment on about the facilities that were available to them for producing a semen sample for analysis. Men produced their samples at either at home, district general hospital or the fertility centre. One man, who produced his sample at the fertility centre said:

*'...and the room that was offered to us anyway was quite small but it was alright, it wasn't too bad it was clean and the facilities were good and they offered us a magazine and everything and it was a little bit weird and I could hear people talking and I was thinking this is not quite right (laughs) but I thought if I'm gonna have to do it anywhere I rather do it here...' (INT-01:37).*

Participant 4 produced his first semen sample at home because there was a lack of facilities to produce the sample at his local hospital. He explained that he lived far away from his local hospital, and therefore found transporting the sample to the hospital on time difficult. He found it very stressful the first time he did a sample, to have to produce it and then rush to take it in on time (within an hour from production) for analysis. He said that this process created some doubt in his mind whether the first sample was analysed correctly and on time. He said:

*'In (specific hospital) it was very much like 'there's the test tube go and find somewhere (to produce the sample), and by the way you need to get it here in such and such a time from wherever you live', and I am thinking, how am I supposed to get it there in an hour? How am I supposed to produce a sample, then having to try and get to a hospital in the car whilst trying to keep it warm and get it to the right pathology lab...it was a bit problematic to say the least and there was no real facilities to do that...and I suppose that was one of the other reasons that I thought there may be the (sperm count) problem because maybe I did not get there in time...' (INT-04: 31)*

Because of his experience described above, he then went on to explain that he found the facilities and the idea of producing his semen sample on site at the fertility clinic 'absolutely fine'.

*'I just feel that the facilities here were easier to use and I had more confidence. Here, it was absolutely fine, I had every confidence that once the sample was produced it was in the lab within minutes of it being produced, so I've had more confidence that if there was any problem in delivery or getting it to the lab, that here it was right and it was correct' (INT-04:31).*

Participant 6 explained that he experienced difficulty in producing a semen sample for analysis:

*'I was examined and then I was told to try and provide more samples. I had to come in here and try and provide a sample here, which I didn't manage to achieve, I think I came here two or three times and I couldn't achieve anything here either' (INT-06: 54).*

When asked why he found it difficult to produce the sample he said that he did manage to produce his sample at the end, but the whole experience felt unnatural and it was uncomfortable because of the background noise around the production room:

*'I just think it wasn't really a natural thing for me to do, it wasn't [laughs], I wasn't comfortable...I just think it was the circumstances and also when I was here we could see people working and staff and people interviewing and other stuff going on within the building... it's just no real. I mean I wasn't comfortable anyway, don't get me wrong, but it was just the fact that you could hear stuff going on, people talking... it didn't seem right whatsoever me even being here doing this sort of thing to be honest. There is the background noise and stuff like that and I mean I was hearing people having proper conversations [Laughs]. I mean I wasn't comfortable with that, you know, people talking about what they watched on TV and stuff like that [laughs]' (INT-06: 90).*

On questioning about what he thought of the facilities, participant 8 said:

*'It's not really a great environment to be in. You know what I mean, it's not as if it's, you know, it's just a room with some magazines and that was it. So I wouldn't say it was homely or anything like that, it's*

*probably a little bit more, clinical than I would've expected'* (INT-08: 83).

Participant 9 had to use his local hospital's toilet facilities to produce his first sample. When asked what his experience of using the fertility centre's facilities was, he said:

*'...well, it is a room. Better than the (hospital) toilet, but where the room is situated you know, you have people walking up and down, you can hear them... and directly opposite the room there's, like a, a shelf or whatever, like a table, where people, the nurses do their writings and so as soon as you come out of the room you will see the nurses there doing their report writing and things like that. But you know, it could be better located obviously it wasn't private enough, but as I said, it's better than doing it in the (hospital) toilet'* (INT-09: 85, 86)

Participant 10 also criticised the lack of privacy in the room to provide the sample at the fertility clinic. He said:

*'... a bit nerve wracking because you can actually hear patients talking to doctors in the room which puts you off a bit and, the noise is in the background, because you can hear doors slamming, you can hear patients talking to doctors... the first time it's a bit off putting, but then the second time then the third time, it was just like, well, I just, I know what I'm here for, just do it, and the quicker you've done it, the quicker you can go and get on with your day. But I think for your first time it's a, it can be a bit nerve wracking when you hear, you can hear people talking, you can hear people rustling paper or what have you. You wonder if they can hear what you're doing'* (INT-10: 85).

#### **4.4.4.3 Recommendations for facility improvements**

Participants were asked if there was anything they would have changed in order to make the experience more comfortable and reduce the psychological burden of having to produce a semen sample in a clinical setting. Some of their suggestions are summarised in the quotes below:

*'...the privacy issue with people going past, because you can hear the nurses, the talking outside and this was the worst, yes. It would have to be more private... it still going to be giving a medical sample from something that you would normally do as leisure, I suppose, but yeah it's not having people go past'* (INT-02: 49).

*'I'll tell you what's distracting, right, is the people on the other side of the door, not the window, because that's nothing, it's the door you've*

*just come in, you can hear the nurses on the other side of the door chatting, like, about the day, it's not soundproofed or anything. So that's quite off putting' (INT-13: 516).*

*'I would have taken the magazines away for sure. They weren't very helpful because you realise the reasons you are doing it, which aren't the reasons you might do it otherwise and therefore it just feels all very strange. And the room itself, it's very clinical, bright lights all that kind of stuff. And yeah, it's all just a bit odd really' (INT-07: 66).*

#### **4.4.5 Lack of specific cause for the azoospermia**

As discussed in the introduction chapter of the thesis, a specific cause is not identified in up to 50% of cases of azoospermia. Nine out of 15 study participants had unexplained azoospermia. The portrayed emotion was frustration for the majority of participants who could not be provided with a specific explanation and a reason for their diagnosis.

Participant 2 was asked how he felt about the lack of explanation for his problem and he said:

*'My frustration was rife, my frustration...just because I thought may be, how common is it, how often does this happen? Is it a relatively new thing? Is it something that nobody understands just yet... and it was just the lack of information which is like maybe it is just a brand new thing that they have discovered but it is new I've never really heard of anyone but I've never looked at the problem...' (INT-02: 49).*

Study participant 7 said:

*'That's obviously quite frustrating. I'm normally somebody who likes to know how things work, cause and effect, and so that's quite difficult...just to not know. I have seen a number of specialists now but nobody has been able to give me any idea of a possible cause. They just don't know...' (INT-7:86).*

He then continued to say that he was concerned of the possibility of passing on an undiagnosed genetic cause of his azoospermia to his offspring, if treatment was successful:

*'...if we if we if we go down the route of having treatment, one of the questions I'm now asking myself is am I passing on a problem to another generation potentially? If it's successful, has this been a*

*problem from birth? I just don't know. So that's quite frustrating, not knowing why' (INT-07: 88).*

Participant 8 said he found the fact that he could not be given an explanation, shocking:

*'Well, it was, it was quite a shock, you know, because nobody could tell me what the problem was, because the doctor examined me physically and said there was nothing, he couldn't explain why, you know, couldn't explain why... there's no reason...'* (INT-08: 39).

Participant 15 said that the most difficult aspect about the diagnosis of azoospermia was not knowing why:

*'Not knowing why...I think that's probably the hardest thing... I always wanted to know why, and not really understanding or never kind of progressing and getting a sound answer. I think if there was a natural pinpointed reason that I could say, 'it's OK, that's why'. Yeah, it wouldn't necessarily make the situation any better, but I guess it would kind of remove some of the frustration maybe...so you're not guessing or wondering or thinking you know 'why' or 'why me' kind of thing... I think still the thing for me is the whole question of why, any extra help that would help find out why I am in this situation then I think obviously that would be great'* (INT-15:43, 124).

One participant said that he wasn't too concerned about not knowing the exact reason for his azoospermia and that he learned to accept the diagnosis as it was. When he was asked about how he felt not having a specific explanation for his condition he said:

*'I can accept that things are the way they are...that's my philosophy that's been quite entrenched through this process... that is the way it is. That doesn't bother me to be honest with you so as I say it's, you learn to accept this is the way it is...I've got a friend who's just developed MS (multiple sclerosis) and that's what happens, so it could be worse'* (INT-2: 87).

When asked how he felt about not having a specific explanation for his problem, another participant said that he was not happy not knowing why, but he explained that he was optimistic and that there was always the possibility of finding out in the future because of research:

*'I would like to know why but I just accept the fact that we just can't, we don't know yet, we don't know everything and we couldn't possibly know everything... that's why there's research, so I think I always go on the side of, at some point we might do' (INT-04:57).*

One participant said that he could not put a closure and move on because he couldn't find out why:

*'I cannot like, put a closure and move forward, you know' (INT-12: 99)*

A potential cause for the azoospermia was identified in 6 out of the 15 study participants. The following quote describe how participant 15 felt about his diagnosis of Klinefelter syndrome (a genetic condition) at the age of 36:

*'...it's a bit strange to find out after thirty six years that I've got a medical syndrome... I didn't know anything about it until a couple of months back... I thought I was just a normal bloke, but obviously I've got a genetic problem, that's why I am infertile, so, it was good to know that...it's reassuring in a sense that we were sitting before thinking well why, why us, I suppose but at least I know, there is actually something wrong with me as well, and it is not something that I did' (INT-14: 73, 81).*

#### **4.4.5.1 Past experiences**

All participants said that they had thoughts whether past lifestyle choices could have caused their azoospermia. Men questioned their past behaviours and lifestyle in order to try and identify possible links with something they did in the past that could have caused their azoospermia.

Participant 1 acknowledged that he had spent a lot of time trying to think if any of his past behaviour could have contributed to the problem. He explained how one of his mother's comments about his past use of recreational drugs hurt his feelings:

*'I have spent most of my time thinking about it... I have spent most thinking, what have I done wrong? Why is this the way? I look back at the family and I've got a really large family and they have all had kids. Then I started thinking about everything else that has ever happened, and one of the first reactions my mother said to me when I*

*told her: 'it's all them bloody drugs that you smoked when you were younger'... and it really hurt to be honest...' (INT-01: 31).*

And he went on to say that this was always at the back of his mind and that he was trying to distract himself from this by keeping occupied with other things:

*'I think for a long time I'll always be quizzing myself over what it is (the cause), until maybes in the future someone comes out with an answer...this is one of the things maybe I've done, that I'm just not sure at the minute, and I will keep beating myself up about it all day every day, but I try and keep it off my mind with work and things like that keeping me busy...' (INT-01:31).*

Participant 3 said that despite trying to think of things he did in the past or a possible genetic link from his family history, he couldn't think of anything to explain it. He said:

*'I thought obviously it might be something in my genes, if it's skipped down, and I really didn't know what to make of it to be quite honest, my head was just all over the place' (INT-03:34).*

Participant 4 said that he asked his parents if they were aware of any medical problems that he had as a child that it could have caused this, but there was nothing in his past medical history.

*'I asked my parents whether or not there was any kind of history of it or anything like that and they said there's been no problem anywhere else in the family that they know of where this has ever happened' (INT-04: 25).*

And he continued to say:

*'But yes, I did try to rationalise why and I think because I had some medical sciences background from university, I was trying my best to think in my own mind what it could be... because I would consider myself healthy, I've never, touch wood, never had a broken bone, I've never really been in hospital, never had an overnight stay in hospital ever and I didn't quite get why me, why it would be me that would have that' (INT-04: 25).*

He then went on to explain that his fertility problem worried another member of his family, his brother, and prompted him to go and see his GP to be tested:

*'It obviously worried my brother significantly enough that he decided that he was going to go and see his own GP to, to find out if he had a similar problem err to me erm and I don't know what the situation is with that result at the minute'* (INT-04: 25).

Participant 5 considered his past lifestyle choices but he denied that any of these could have caused his infertility. When he was asked if he thought there was anything he did in past that could have caused his infertility, he said:

*'No, I mean, I've more or less lived a healthy lifestyle and haven't done anything really I shouldn't to have that effect'* (INT-05: 31).

Participant 7 tried to establish if there was any family history of fertility problems that could potentially explain his azoospermia, but he could not identify any:

*'The only thing that's crossed my mind is that I'm aware that my parents tried for up to five years to conceive me and they were twenty nine at that point when I was born'* (INT-07: 48).

Participant 11 tried to establish whether there was any link between strenuous exercise or exposure to environmental factors and his infertility:

*'There is a couple of things that I know don't help. One of them is I used to do lots and lots of cycling when I was younger and lots of exercise, so I don't know whether, being very very active when I was younger has had an effect... I also used to live next to a couple of mills, down in Burnham, and one of them used to use chemical dyes and they used to have a discharge pipe that used to discharge, well, allegedly, steam but it didn't smell like steam when it came out, so I don't know if I reacted to anything that could a been in that...So whether that's had any long term affect, I don't know'* (INT-11:31).

#### **4.4.6 Consultation without partner present**

Men were asked whether they felt the need at any point to speak to a member of staff or a counsellor without their wife/partner being present. Fourteen out of 15 men said that they shared the diagnosis with their partners/wives from the outset and that they didn't feel the need to have any private discussions without them present.

Participant 2, who was interviewed on his own, when asked if he would have liked to discuss anything without his partner present, said:

*'No. I felt a bit weird coming here on me own today actually. We have been (coming here) together, so no. No, it's been a team effort' (INT-02: 137).*

Participant 3 said:

*'It's been fine; she would have been here today but she had to go into work. We've done everything together through the whole step of the way' (INT-03: 97).*

*'No. I don't think there was anything that I needed to ask, in private without her there at all' (INT-11: 183).*

*'I never really thought or felt like an urgent need to say OK well, I need to kind of get just me and somebody else to go through this. Any information obviously that came out I would relay to my wife anyway. Like I say we're obviously both in this together. So I've never really felt the need to do this without her. I say we are a team, so to me it seems like we should both be there and going through it together' (INT-15: 115).*

Only one study participant said that he would have preferred a counselling session without his partner present. He said:

*'...the fertility treatment as a whole has been us together, but sometimes I think it would have been helpful is that I would have preferred something on my own, because as I am speaking to you now, I would expect her to be saying 'Oh, I didn't obsess about looking up donors, I was just being proactive', but I felt to me she was (obsessed), and I wouldn't be able to say that in the same room with her. So yeah, it's difficult... I would have probably thought that a counselling session that's just specifically for me would have helped' (INT-04:79).*

#### **4.4.7 Communication and information seeking through online support groups and forums.**

Participants were asked if they looked for information and advice through the internet, on websites or forums. Some participants looked for information over the internet themselves, but the majority did not spend any time looking online. Instead they said that it was mostly their partners that looked online for information. The

general feeling was that there was lack of information about male infertility in online forums.

Participant 1 who admitted looking at some websites said:

*'I did actually find a good one (website), I can't remember what it was called, and I just thought I'd read it...and I did actually look at some other stuff online and the anatomy of a man, I looked at that quite a lot, and I was thinking of every little pain I'd ever had in my scrotum because I did have little aches and pains and things like that. So it's definitely a subject I've gotten into a little more. There is a few people talking online about it, but there wasn't a lot, there wasn't a lot of comments but I think the advice I got was off the one or two (websites) I did read'* (INT-01:107)

Some participants admitted that it was their partners that looked on the internet to obtain information and advice about male infertility. When asked if he looked online for information about his condition, participant 11 said:

*'No. xxxx (my partner) did all that kind of thing. She was looking on the internet. She didn't find a lot to do with men and as I say, with regards to discussion forums and stuff like that, there's not a lot – well, she didn't find much anyway'* (INT-11: 163).

When asked why he did not look online himself, he jokily said:

*'Because she's better at looking at the net at these things than I am [laughs]. She's a much better researcher than I'll ever be'* (INT-11:167).

One participant said that he was happy to read quotes on the internet, but only when his partner pointed these out.

*'She goes on it (the Internet) constantly. Yeah, she's been on it all the time. I mean she was going on and then she was like saying, 'oh do you want to read this'? So, like, I would read it but she was the main one looking online'*(INT-04:75).

Participants said that they were reluctant and avoided looking for information over the internet because they did not want to 'scare' themselves. They expressed the concern about the scientific validity of the information found on the internet and therefore appeared reluctant to believe what is true online. They said that it was difficult to believe the information on the internet because it was not possible to know whether it would be applicable to them and if it was backed by scientific evidence.

When asked if they looked on the internet for information and support, those participants said:

*'I didn't really (look online) because I didn't want to scare myself... there is a hope over there (the operation), you know, and I didn't want to end up stressing and straining. I didn't, I didn't start looking for extra help online at that point' (INT-04: 73).*

*'Yes (I went on the internet) and certainly xxxx (my partner) is doing that much more than I have, but we've both looked into that. I mean, the internet in some ways is a fantastic resource, but I still understand that a lot of the internet could be just people vending their own issues and it's not all scientific or research-based or anything, but it's really useful to gather information. So, yeah" (INT-07: 126).*

*'No, I didn't. It's just, I think with [sighs] the internet, you never really know how valid the information you're reading is. And you know, there are probably legitimate sources, but at the same time, it's somebody giving an opinion or a catalogue of what they've been through, sometimes it's not necessarily the whole picture. So we actually consciously decided to stay away from doing that, just to avoid making the situation even worse' (INT-15: 107).*

Participant, who stopped using anabolic steroids for bodybuilding, said:

*'I didn't want to read up about it, because you can read the wrong things on the internet. The internet can be a bad tone as much as a good tone, you know. But I did look on the internet, you can't help it, sometimes it's right in front of you, so, sometimes you really just want that, that quick fix answer. Yeah, I looked into the forums and you read stuff and obviously I was into my bodybuilding and a lot of the people I trained with, they were into bodybuilding and they all said, 'Ah, you'll be OK, such and such's wife fell pregnant and he's going a competition and, you know, he's doing this and he's doing that and he's taking whatever and it'll not be that', and then you read up on the forums and you hear of all the pros and all the cons, but the pros always seem to weigh out the cons on specialists websites, because it's all about the bodybuilding, so they're not going to say it's wrong, it's harmful' (INT-10:37).*

One participant said that he looked online for details about his sperm retrieval operation:

*'I've been on to look at the operations etcetera, antiseptic, what you need to do like before I had my operation, to see what that was like,*

*just some basic stuff like that. And I've had a look at my genetic condition, and there is nothing I can do about it, so. Nothing I can do about it...'* (INT-05:129).

Participant 9, who had very strong religious beliefs said that he never considered looking online:

*'No, I never, I never... looked at any websites. I have known people who have had similar kind of situations like myself or my wife, and they're Christians, and the miracle has happened, so I just, I just stood on the word of God basically'*(INT-09:205).

#### **4.4.7.1 The Internet as a means of social support**

Two participants said that they saw the internet as a form of emotional and social support, because finding out that there were other men experiencing the same problem, made them feel less isolated. Their comments are summarised below:

*'Well this (knowing others have similar problems) doesn't let you feel alone. It doesn't make me feel any better, the fact that I can't (have children), just because somebody else can't either, but it just does makes you feel that you are not isolated, you're not a one-off, you're not the only person in the world who can't, you know?'* (INT-11:177).

*'I haven't actually joined a forum, or got on it interactive, but I have read a lot of comments on forums, you know, I know I'm not the only one out there, yeah'* (INT-12: 115).

*'I did go in the odd forums just to really see what other people were thinking. I mean I still do my research now on little things, you know, people that have had his procedure done. But not for support as such, just really to see what other people are going through'* (INT-13:381).

#### **4.4.8 The experience of having a physical examination**

##### **4.4.8.1 Expectation with regards to the physical examination**

The majority of participants said that they expected a physical examination at some point during the investigation, and that it 'was fine' to be examined. Some of their comments are summarised below:

*'I had a previous examination at Durham, where they basically felt the anatomy to see whether or not everything was there and if there was any issues. And, again, yes I did expect to be examined (at the fertility clinic) ...'* (INT-4:39).

*'I expected some sort of physical I suppose, in the back of my mind but, it just seemed to happen so quick. Everything just seemed to happen so quick. I suppose that's the best way. It was fine, a bit embarrassing but it was fine' (INT-05:41).*

*'It was really quick, the guy (doctor) explained everything that was going to happen and yeah, no discomfort or embarrassment or anything, it was fine' (INT-07:76).*

*'I'm very much, a kind of person who if it has to be like that, it doesn't bother me at all. You know, it doesn't matter if it's a male doctor or a female doctor; it's what I need to do to try and go further. You know, it didn't bother me at all' (INT-08: 87).*

A few participants mentioned that they did not expect a genital examination, and that they would prefer to have been informed in advance.

Participants 6 and 11 said:

*'That wasn't expected, there was nothing mentioned in the letter you wrote out to us, nothing to say, you know, expect an examination. To be honest I think we just came in here and just didn't know what to expect. I just didn't know... I was fine with it, you know, just caught a bit off guard really' (INT-06:72, 74).*

*'I didn't expect one, but I wasn't bothered about having one' (INT-11: 69).*

Participant 5's partner, who was present during the interview, said that she felt embarrassed because she did not expect to be examined herself when she attended a clinic appointment with her partner:

*'The last time I came, not so long ago, I got examined too. When I came I didn't expect to get seen to, and I felt embarrassed' (INT/P-05:47).*

Two participants mentioned that they did not expect to have a rectal examination and that they found it uncomfortable.

*'The TRUSS (trans-rectal ultrasound examination of the prostate) was obviously uncomfortable, the probe' (INT-02: 61).*

*'I suppose I was very much aware about the front part (of the examination), but obviously he did check for blockages as well*

*internally (rectal examination) and I wasn't necessarily expecting that, and that came as a surprise' (INT-4:39).*

#### **4.4.8.2      *Feeling nervous and embarrassed***

As discussed above, the majority of men expected to be physically examined during the consultation at the fertility centre. Five of the men said that they felt nervous and some found the experience 'daunting' initially.

Participant 1 said:

*'To be honest, I think my penis has been out to more people in the past couple of years than it has in my entire life, I have got quite used to it, but it was a bit daunting at first' (INT-01: 41).*

Participant 2 explained that the presence of a female examiner made him feel uncomfortable and embarrassed.

*'I had to force myself to take my trousers down, I think it was a female gynaecologist at first which may have been a factor, everybody else (examining me) since the second operation has been male, so that seemed to be better for some reason' (INT-02: 61).*

The following two participants felt nervous about the examination. Participant 10 added that he was glad about the confidential approach at the fertility centre.

*'It was a bit nerve wracking to be quite honest, because obviously no one's ever felt there before, like gentleman wise, but, it was, it was alright after. It wasn't a shock, I knew' (INT-03: 45).*

*'I was quite nervous about that (the examination), I was quite nervous about someone prodding around. But it was gentle, considerate and the confidentiality as well was great, the patient confidentiality's brilliant within the Centre' (INT-10: 116).*

Participant 15 described how embarrassed he was and said that that he felt it was unnecessary to have to be examined on two separate occasions:

*'Well I suppose, for me there was kind of two factors really. I mean there's the initial kind of embarrassment factor. To be honest it wasn't really the first time I'd had an examination in that area. So that wasn't a big deal as maybe it could be to somebody who hasn't before. The actual process was actually quite painful, the first time around. More uncomfortable the second time around. But I believe like the point of*

*the examination, was to get the same result. And obviously because I was quite uncomfortable I just thought well, if there was a record of the, the results the first time the examination was done it might have removed the, the need for the second time. So I could have lived without the second one. I guess it's just standard' (INT-15: 47).*

#### **4.4.9 General comments about the clinic and staff**

All couples had positive comments about the clinic staff, which were described as very helpful, sensitive and supportive. One couple said:

*'Once we got here we felt welcome and everyone was dead polite and friendly...they made you feel comfortable, so we weren't like nervous to say anything or anything like that' (INT-03:37).*

Some participant's comments are summarised in the quotes below 14 said:

*'The way everybody's handled it here, it's been very, very good and I think at times my own doctor(GP) has been a bit blunt, but in here they have just been very helpful. I couldn't praise more everybody in here because everyone's been so nice' (INT-14:165,167).*

*'The nurses and everyone's lovely that works here, we like them all, we've got to know them [laughs] quite well for being here so long' (INT-12: 267).*

*'They couldn't be any better, they're lovely, I cannot fault them. Yeah, the nurses were lovely, one nurse was crying at one point when it didn't work for us, they just were really like family, weren't they, they were lovely' (INT-13:388).*

*'I imagine it's not an easy job for them to do as well, delivering like you know, such bad news. But they were very supportive; they were very good at answering questions. They were very good at offering help and counselling and all that kind of stuff. So I think generally that was very well handled' (INT-15:97).*

## **4.5 Summary**

The majority of men learned about the diagnosis following a period of trying to conceive with their partners without success. Some couples and the male partner in particular, expressed reluctance to seek help immediately. Several men said that he always assumed infertility to be 'a woman's fault' and never expected that such problem could occur in men.

Participants experienced a number of different emotions during the process of discovering their infertility diagnosis. Shock, disbelief, devastation and sadness were amongst the most commonly expressed emotional reactions. However, the diagnosis of infertility was not a surprise to all the men interviewed. Some men explained that they were suspicious about the possibility of a personal fertility problem, because of previous experiences that led them to believe they could be infertile. Men perceived that their GPs lacked knowledge concerning male infertility and expressed the concern that on some occasions the diagnosis was given in a non-sensitive manner, with a lack of empathy.

The visit to the tertiary fertility centre had an important role to play beyond simply finding out about available treatment options. One of the biggest concerns about visiting the tertiary fertility centre was the lack of information on what to expect upon the visit. Participants stated that they felt 'nervous' mainly because they did not know what to expect during the visit and because they themselves had very limited knowledge about reproductive health and lack of experience in discussing sensitive issues openly. Referral to the fertility centre was seen as a reassuring way to get some answers to their problem and help them move forward. Finding out that expert help was available, provoked a sense of hope that the diagnosis of azoospermia was not 'the end'. Men and their partners saw the visit to the specialist clinic as an opportunity to get answers and real pragmatic help for their problem. Patients considered gaining an explanation for their problem very important, and when no obvious cause could be found, participants said that this was very 'frustrating'. Men questioned their past behaviours and lifestyle in order to try and identify possible links with something they did in the past that could have caused their azoospermia. Visiting the fertility centre made them feel less isolated and 'not alone' and, as they realised that other couples are suffering with similar problems.

The majority of men expected to be physically examined during the consultation at the fertility centre and said that it was 'fine' to be examined. Some men said that they felt nervous and some found the experience 'daunting' initially. With regards with producing semen samples for analysis, all men said that it was 'something they had to do', because there was no other way of finding out the diagnosis, and expressed some degree of embarrassment and discomfort at having to produce a semen sample under these circumstances. The majority of participants felt that the semen sample production facilities lacked the expected degree of privacy.

Two participants said that they saw the internet as a form of emotional and social support, because finding out that there were other men experiencing the same problem, made them feel less isolated. The general feeling was that there was lack of information about male infertility on online forums. Men said that it was mostly their partners that looked online for information. They expressed concerns about the scientific validity of the information found on the internet and therefore appeared reluctant to believe what is true online.

Not knowing how long the treatment was going to last and the uncertainty of whether it was going to work, was one of the most difficult issues to deal with. Participants described how the couple's lives were pretty much 'on hold' because of waiting for follow-up appointments and worrying about the investigation results. Seeing a number of other couples being referred to the fertility centre made them feel less isolated, because they found out that there were other people 'out there' with similar problems.

## **Chapter 5: Disclosure of the diagnosis, means of coping and impact on men and their relationships**

This chapter explores the experience of disclosing the diagnosis to close family members, friends and colleagues at work, and the reasons for non-disclosure in some cases. In the process, it also explores what means men used to cope with the diagnosis. It then reviews in detail the impact of the diagnosis on men's lives, and in particular the impact on their relationship with their partner/wife, friends and family, and everyday life, including work.

### **5.1 Disclosure of the diagnosis**

All participants in this study were comfortable talking to the researcher about the diagnosis of azoospermia and they shared the diagnosis with their partners/wives. A few couples avoided sharing the news with close relatives or friends, at least initially, and when they felt that they had to disclose the diagnosis, they expressed discomfort during the process. None of the participants stated that they felt rejected or blamed by their partner and /or family upon disclosing their condition to them. Only a few chose to inform others beyond their close family members. Some couples decided to keep the news strictly to themselves. Participant's comments reflected the fact that there is still a degree of stigma attached to the diagnosis of male infertility.

#### **5.1.1 Disclosure to family members**

The majority of couples decided to inform their close family members of the diagnosis. Participant 3 said that he only told their parents and sisters, but no one else outside the family.

*'I told my parents, yeah...our sisters known that, but that's it. We didn't want to tell anyone else'* (INT-03: 83).

Participant 5 said that apart from his parents, he felt obliged to tell his brothers, because if a potentially genetically transmissible cause was the reason for the azoospermia, this could have had implications on his brother's fertility. He said:

*'There's only my parents know, yeah, that's it at the minute...I also mentioned it to my brother [for the reason I mentioned earlier], I mean it's up to him how he takes it, whether he wants to try to look into it further for himself, that's up to him'* (INT-05: 94, 100).

One couple said that they hadn't disclosed the diagnosis to their family at the point of the interview. When questioned if their families exerted any pressure on them to have children, they said:

*'I think at our age when you've been together a long time like we have, you know, it occasionally crops up in conversation... 'have you never thought about it or why haven't you had children' but it's never been an in depth discussion with anybody'* (INT-07: 118).

*'It's more one of those comments, you're knocking on a bit now, you better get some bairns kind of thing'* (INT-07: 119).

Participant 9, who had a very strong religious background said that he told the pastor at the local church, and also his close family members:

*'Well, the pastor of my church knows because he was praying for us, so he knows about the situation. My family know, my mother knows, my brother knows, my sister know... and I think that's it basically'* (INT-09: 143).

Participant 14 was diagnosed with obstructive azoospermia secondary to cystic fibrosis (a genetic condition). He said that he initially told his close family only, and commented that his parents were blaming themselves for his condition. He considered telling his very close friends, but only if he needed to.

*'My family know, obviously. Her family know, my brother... they're basically the only people I've told. At first my parents thought it was their fault. I said well, it's not your fault. It's obviously when I've been conceived. My mother's one of these people that takes everything to heart, so I said well don't, it's nothing to do with you. I haven't told any of my friends, I'll only tell, I'll only tell them when it's right. I mean obviously these are my friends I've grown up with, who I'll probably, continually be with for the rest of my life. But I'll only tell them when I need to tell them'* (INT-14: 59).

Two participants described situations where inappropriate comments created some friction between family members. Their comments are summarised below:

*'All her (his wife's) sisters have children and the worst, it was hearing about what she was going through because they're all talking about the kids and everything and she is just sat there and she was saying (to her sister), going through this treatment, she was not sleeping very well because of the stress of it, and she says, 'oh, I got insomnia' and you know her sister turns round to her and says, 'you can't have*

*insomnia, you don't have kids'. And, yes, exactly so that was, you know, that was getting really upsetting for her' (INT-02:123).*

*'It was upsetting at Christmas when my brother wouldn't tell us, he didn't want to tell us that his wife was pregnant because he didn't know how we would take it. He thought that, because we had been trying so hard and he knew how much we wanted it and they just [snaps fingers] fell like that, they just stopped using something, I think she had been off the pill four weeks and then she was pregnant. So he thought that I'd stop talking to him and that we'd have a fall out and he felt very anxious about telling us...and my mum ended up telling me that his wife was pregnant, because they didn't know how we were going to react. It was upsetting to think that your own family couldn't tell you about such a joyous thing that was such a happy, all because of what we were going through. So that was quite upsetting for the two of us' (INT-10:93).*

### **5.1.2 Telling close friends**

The only time men disclosed the diagnosis to a close friend, was when they knew that this friend had a similar fertility problem. The reason they quoted is that they felt that only friends with similar problems will understand them and will be able to 'share' similar thoughts.

Participant 7, who was interviewed together with his partner, said that he disclosed the diagnosis to a close friend, only when his friend confessed to him that he was going through a similar situation, having been diagnosed with a testicular tumour. His partner seemed to be unaware of this at the time, so he apologised to her during the interview. He said:

*'...partly through agreement we haven't spoken to anybody about it. And that's not quite true and you don't know this so I apologise now [to his wife], but I have a friend who's not a close friend... so I have a friend who is not one of our close circle of friends, who confided in me that he'd had a cancerous tumour on his testicle. He had a testicle removed because of cancer and you know, I then confided in him that I was going through this process. But he's the only person that I've told out of everybody I know, yeah'" (INT-07: 109).*

Participant 10 explained that he disclosed the diagnosis to a close friend at the gym, who had fertility problems and had to have IVF treatment. He said that he had long conversations with his at the gym, and his friend was understanding and tried to boost his confidence by saying things like *'It's amazing what these professional*

*brains at them places can actually do with one sperm, it only takes the one sperm’.*

His exact words were:

*‘Yeah, I spoke to my training partner at the gym, I spoke to him a lot. He’d had IVF, so we used to have some long conversations about like, what he went through..., what his wife went through...so he was trying to keep me boosted up, but it didn’t work because it’s only yourself that can keep yourself motivated and positive... But I did confide in him a lot, because I asked him what he went through, what his wife went through... and then obviously I stopped training, so I didn’t really go and see him, so, and then it was just me and my wife that spoke about it’ (INT-10: 87).*

When asked if he ever told anyone outside his close family, participant 15 said that he spoke to a very close friend, but he didn’t go into details about his condition.

*‘I have spoken to my best friend about the situation. He’s the only one I’ve ever told, but even then I didn’t go into details and say that there was a specific problem with me, I just said we were having problems, without going into the details. So I’m OK with it, but I wouldn’t want anybody else finding out if that makes sense’ (INT-15: 59).*

### **5.1.3 Telling people at work**

Disclosure of the diagnosis to colleagues at work, and in particular their employer, was an important consideration for couples, especially for those that required time off work to undergo a sperm retrieval operation or IVF treatment. Men in general were reluctant to disclose the diagnosis, and if they had to request time off work, they avoided giving the true reason.

Several participants said that they lied to their employer and work colleagues when it came to requesting time off work. One participant said that he ‘made things up’ and others disclosed that they were going through fertility investigations, but did not give the exact details of the problem. Participant 1’s comments when he was asked about whether he disclosed the diagnosis to anyone at work, including his boss, were as follows:

*‘...I just made a thing up saying I’ve got something with my blood pressure and all that, and may have to be off a while. He is (his boss), I hope going be alright and he hasn’t asked too many questions... the office is quite tight knit really a little bit it’s like there’s 30 or 40 lads working there and they all know each other in and out of work and all*

*the rest of it and I just don't want it out on the shop floor...'* (INT-01: 95).

Another participant said that he told people at work, but did not disclose the exact details of the diagnosis. He said:

*'I have mentioned it...to some people at work. I've told people what we're going through, but I haven't told them the ins and outs...I have obviously had to tell people like my manager...I've had to have an operation and stuff like that, which they've they have been really good, understanding'* (INT-05: 94&100).

When asked if he disclosed the diagnosis to anyone at work or his employer, participant 10 said that he did not give any details:

*'Work knew, they knew I had to go for tests, I had to tell them why I was going and that I was trying for a baby. But I didn't speak to them in any depth of like what my results were, I just told them that we were trying for a baby and I needed to go and produce samples or I had to go for a consultation, so I needed time off. But, I never went into any detail with my employer. He didn't need to know'* (INT-10:91).

He also explained that his partner was reluctant to mention to her work employer that she was trying for a baby, in fear that she will be dismissed if her employer found out that she was trying to get pregnant. When asked whether his wife told her work colleagues about the problem, he said:

*'She never told her employers of what was happening because I think she was worried that they were going to think less of her and that she was going to leave or they were going to try and manage her out because she was trying for a baby. So her employer doesn't know still, that she's trying for a baby or that we're registered with you and what we're going through at the minute, they have no idea, as far as she's concerned we're not looking at babies at all at the minute. So, that's how she's just keeping it'* (INT-10: 91).

Participant 9, who was from a strong religious background and was coming from a culture where having children was very important, said that he was not comfortable telling anyone at work because he felt embarrassed:

*'Obviously I don't discuss it with people at work... it's not something you discuss with people at work. When people ask, they ask at work,*

*'Aren't you going to have a child?' 'Oh yeah, definitely, yeah'. Ah, when are you going to have one? 'Ah, in God's time'. So that's where I leave it' (INT-09: 143).*

Participant 13 was embarrassed to tell the whole truth about the diagnosis of azoospermia, highlighting once again the degree of stigma attached to male infertility.

*'...I go to work and say, 'Ah well, me- 'I've got sperm', like, I always try to say there's sperm there. But, 'it just going the wrong way' and I make a joke of it, you know... 'they're, they're going round in circles'...I still can't bring myself to tell the exact truth' (INT-13:189).*

#### **5.1.4 Reasons for non-disclosure of diagnosis**

A high level of stigma attached to male infertility was one of the dominant reasons for which men felt reluctant to disclose the diagnosis to others. This was reflected by the secrecy expressed by the majority of men interviewed.

Participant 15 said:

*'It's obviously not information I've wanted to share with everybody. Certainly not my friends, because even though I may feel that it doesn't necessarily make me feel of any less of a man, obviously there you know there is that stigma in essentially groups of men and friends and everything like that. It does have that negative connotation so it's definitely something I wouldn't want to share with my other friends' (INT-15: 59).*

One couple said that they kept the diagnosis strictly to themselves. The man explained that his azoospermia was his 'biggest secret' because of the stigma attached to male infertility. He said:

*'I am very secretive about this, because I can't deal with it, it's my biggest secret, it's not good. It's just one of them big things...I said to my partner, with ladies infertility it's more accepted as a word, but with men I think looks totally different...It's embarrassment more than anything else and people knowing your personal problems. So, I just would hate anyone to find out' (INT-12:109).*

Another reason given by some interviewees was the fear of social ridicule and receiving insensitive and inappropriate comments, especially from colleagues at work.

*'And it's one of the reasons why I won't mention it to anybody at work, I wouldn't want to discuss it at work, is because I wouldn't then want that sort of like, I wouldn't want to compound it with any comments that they may come up with just make me feel worse about it, you know? Erm, it's like a secret a want to keep to myself, as such' (INT-11:129).*

*'People at work are very ignorant...I have, I have threatened somebody at work before, for calling me King Jaffa, or something like that, which in history couldn't produce children in days gone past. So someone, it was actually my boss that actually said, 'Weeheey, Jaffa'. That was the first time round and I was still sensitive to it and especially in front of other work colleagues. So, ah- ah didn't really aggressively threaten but ah did threaten never to say it again, basically. So it can be a touchy matter' (INT-13:201).*

One couple said that they did not disclose the diagnosis to anyone because they were hopeful that treatment will be successful and therefore felt that there was no reason to disclose the diagnosis immediately. The man's comments were as follows:

*'Well partly it's because I'm hopeful that there's going be a positive outcome at the end so therefore there's no need to put our worries and pressures onto other people. I'm still hopeful that there'll be some good news further down the line. I just don't really see that it would help anybody by sharing our problem' (INT-07: 113).*

His female partner, who was present at the interview added:

*'I think personal problems is personal problems, it's our problem, we don't need to tell anyone. Maybe if somebody was going through the same situation then it's different because then you can share thoughts and stuff. But a lot of our friends of the same age have chosen not to have children; they don't want children, so I don't think they would quite understand, which I guess is why we've also decided not to tell them' (INT/P-07: 114).*

Participant 1 said that one of the reasons that they did not want other people to know about the diagnosis is the fact that they knew a few couples that were trying to conceive at the same time as them, and they did not want to make other couples worry about similar problems. He said:

*'I told me partner straightaway but then we kept it to ourselves for a little bit. Even at work I've got some really close friends and the lads who I always go out with, some of them I've known over 20 years...I'm*

*just trying to keep quiet about it to be honest at the minute because I'm just not wanting to slip up in front of too many people because to be honest me and my partner know a lot of people [that are trying to conceive] and just we don't want to get into other people's hopes...we've kept really quiet about it' (INT-01: 43,57).*

Participant 15's reason for keeping the diagnosis to himself was to help him come to terms with his problem gradually. This is because he felt that talking to other people about his problem and 'saying it out loud' made it sound more real:

*'I think, when dealing with it, it's a bit different to keeping it in your head and processing it than saying it out loud. Saying it out loud kind of tends to make it seem a bit more real. I think it's always quite easy to kind of, not necessarily stick your head in the sand, but to kind of just not let it get to you when it's inside' (INT-15:109).*

He then continued to elaborate a bit more:

*'When you're in conversation and you're saying these things out loud; it makes them more true....it means you're having to kind of, I suppose face up to it and deal with it when you maybe haven't necessarily done that yourself inside, but rather than facing it all in one, you're just taking like a little bit at a time. Which, I've always found easier to do...and plus I think, unless it's worth my life, it's not really anybody else's problem to deal with other than mine or you know my wife's. So it's obviously easier to speak to out loud with my wife, but I think with anybody else it's quite difficult' (INT-15:109).*

## **5.2 Means of coping and support seeking**

Participants described a variety of ways that they found helpful when coping with the stress of infertility. These included having a supportive partner and family, staying active and keeping busy, learning more about male infertility and some ignoring the problem.

### **5.2.1 Having a supportive partner and family members**

Participants highlighted the importance of having a supportive partner and family around them. The majority reported that the best means of coping with the diagnosis was the fact that their partner/wife was really caring, understanding and supportive. Men felt that their partner's understanding and empathy allowed them to share their feelings with her, which in turn helped them work together to cope with the difficult situation.

Participant 1's comments about his partner's support are summarised below:

*'To be honest the one thing that has pulled me through it more than anything else is my partner for being so understanding... overall it was my relationship that held me together; if it wasn't for that I doubt I would even be like continuing coming here (the fertility centre) to be honest, I would just see no need...definitely my partner is my strong point'* (INT-01:63-67).

He then said that if he did not have the support of his partner he would have considered engaging in risk-taking behaviour as a means of coping with his diagnosis:

*'xxxx (my partner) really helped me. If I didn't have xxxx (her) then I wouldn't know where I'd be, I wouldn't know what I'd be doing, I'd probably be thinking parachute jumps, or something, do you know what I mean, like a proper risk taker, I'd be like jumping 20 feet jumps in a motorbike by now, but that's what I'm not going to do because I'm going to try for this baby, I'm going to see what happens with this operation. I'm mentally tuned up for it and I'm in the right kind of relationship and I've got the right family round me. The key thing (that helps me cope) was the relationship that we are in...we have bonded better as well I think...'* (INT-01: 67,107).

Men received words of encouragement and reassurance from their partners, which comfort them and helped them come to terms with their problem. The following quotes summarise the comments of a few participants:

*'We have both been open all the way through... that's how we're getting through it and have been as strong as what we have been with it'* (INT-03:93).

*'...my wife was never, ever blaming me to say well it is your fault'* (INT-09:155).

*'You know; she's never said 'this is your fault' or ever said anything. Or even when we've been in conversation and I've said, 'oh, you know, I'm sorry', she's always very quick to say, 'you know, it's not your fault', 'don't think like that' kind of thing. So she's obviously been very upset, but she's also been very supportive at the same time'* (INT-15: 67).

Participant 6's partner said during the interview:

*'I've got used to the idea that we couldn't have children, so it was sort of, I've said that all along so, it was, it doesn't matter which one of us it is...'* (INT/P-06:99).

A few participants said that their close family members were very supportive. Participant 10's comments below describe how supportive his mother-in-law was to the couple when going through further investigation and treatment.

*'Her mum's been mega supportive, she has always [pause]... every time we've got an appointment she's ringing straight as soon [pause]...we can't even get out the place before she's ringing, how's it gone? You know, do you need anything and, her mum has been really supportive'* (INT-10:93).

### **5.2.2 Staying active and keeping busy at work**

One participant reported that what helped him cope with the diagnosis was keeping busy and active, especially at work, which acted as distraction to the problem:

*'...I did try to hold it together... I've got a busy job that keeps me busy pretty much 12 hours a day, 6 days a week...and then I thought wey I'm quite a hard level-headed person normally; if things are quite bad it takes quite lot to affect me...I am quite stern that way...'* (INT-01:65).

### **5.2.3 Seeking help from a counsellor**

Only a minority of participants suggested that it would have been beneficial for them to receive psychotherapy from a professional counsellor. They said that the benefits of seeking professional support included having an independent individual to talk to, being able to process emotions and thoughts related to their personal infertility and development of stress management and relaxation techniques.

Participant 4 said that he would have liked to have counselling, but the donor counselling session offered at the fertility centre was not what he expected.

*'At that point I did know there was counselling available here (the fertility centre), but when we got here it wasn't what I expected because I have had counselling for stress and things like that before. It was just, it didn't seem like get your emotions out, what do you think about the situation? It was very much, these are the donors and it was more of an information session, rather than explain your feelings of how you feel and exploring those issues with someone'* (INT-04:61)

He continued to say that he would have preferred to receive help from a counsellor:

*'And, I think for me, that (counselling) would have been better. That I could have that point in time be able to express what my problems were. Maybe not necessarily with xxxx (my partner) in the room, but being able to discuss all these ideas that were maybe floating around my head and try and get some logical plan or with somebody else to understand what that meant' (INT-04: 73).*

The majority of men said that they were coping well and did not see the need to seek support from a professional counsellor, because they felt that they had good support from their partners and close family members.

The following men said:

*'The Life Centre, they did offer counselling, but I said well, what is the counsellor going to tell me that, you know what I mean, that I don't already know' (INT-09:139).*

*'I never felt the need for counselling or anything' we have always been good for a talk to each other really' (INT-13:381).*

*'Me personally, yes, I am OK because I think with my age and the fact that this (the azoospermia) has now been identified as the reason, I'm coping fairly well I think, because I am coming to terms with the fact that this (having children) may not happen for us but that's been the case over a number of years really. The older I've got the more it's become likely that we won't have children. I feel actually, reasonably OK, I mean it's not keeping me awake or anything like that, you know. It's very disappointing and it's very difficult, but when you go back to the need for counselling and things like that, I don't feel as though I'm anywhere near that kind of thing' (INT-07:145).*

Participant 11 explained that he and his wife did not think that counselling would have offered them any help. In fact, he said that they saw seeking counselling and psychological support as a form of reminder of the 'failure' to conceive and they would prefer to move on with their lives and forget about it. When asked if his emotional needs were met during his visit at the fertility centre, he said:

*'I think it was more of a factual (session), and we expected it to be more factual, than being a place to go for emotional support. It was more clinical and more factual and that's pretty much what we expected. We thought that we would be able to seek reference to emotional support if we needed it from yourselves, from the Centre at*

*Life, but in a lot of ways, I'm not sure if we felt that we've needed that... We've sort of like gone through the process, accepted the results, of course disappointed, but not felt that we need to sort of discuss it any further, in any form of support group, and I don't think it would do us any more good. We've nothing, it wouldn't really help us. If anything, it might drag out the idea that it's not achievable, you know, and as much as anything, we'd probably rather forget, than sort of concentrate on how we're going to go on as a couple, as opposed to a family...'(INT-11: 175).*

Men were asked if their partners felt the need to seek professional counselling at any point. The general feeling was that couples were coping well with the support of each other and close family members, and therefore the majority of men and women did not see the need for professional psychological support. On questioning whether their partners felt the need for psychological support at any point, two men said:

*'She's obviously close to her mother and her sister so she's been able to talk to them about it, so she's been able to gain emotional support from a close group of female friends and family that she's able to talk to about it [pause]... we haven't really discussed it ourselves, because I don't think there's a lot to discuss...I find that a don't know what to say to make her feel better but other women are better at doing that, like her mother...'(INT-11:141).*

*'...she spoke with her mum and her dad, and her best friend as well, she spoke to about this...and there's another one of her friends who's in a sort of similar situation, so it's nice she's kind of got a counterpart or someone who kind of understands, that she can kind of talk to. And I think that helps as well. I don't think it ever escalated to the need of actually having to go and see, like a specialist to deal with this' (INT-15: 77).*

Participant 13's partner said that she could always seek support from her mother, and that she never felt the need for professional counselling. When she was asked if she felt the need for professional counselling at any stage she said:

*'No, not really. There's times if I wanted to talk to anybody else I could speak to my mother. My mother- she had problems having children herself- so my mum was always there anyway. I never felt embarrassed or we didn't feel the need to have outside help as such' (INT/P-13:461).*

#### 5.2.4 *Positive thinking as a means of coping*

One participant said that his way of coping was to philosophise and try to think positive. He expressed the following view:

*'There is worse things in life basically, so you become a bit fatalistic' (INT-02:69).*

Similarly, participant 12 commented:

*'...you have just got to try and stay positive, but it's so hard to try and stay positive when you are getting a lot of negative answers that you don't want...[pause]...it is difficult when you have to be strong and keep calm...we'll live on, we'll soldier on, yeah, exactly, but what can you do?' (INT-12:273).*

He continued to explain how difficult he finds the fact that some people don't appreciate how lucky they are to be able to have children:

*'I mean, like I've got a cousin who, who's got a baby to an ex-girlfriend, that he went through court to try and see his baby through custody, and he, he gets like upset and angry about stuff like that and I think well, you want to think yourself lucky that you've got a baby and what not, as people just don't have a clue really, until it's happening to them...it's like, you know every newspaper, magazine or the telly, there's always somebody pregnant or stuff like that, it's hard for me and my girlfriend, but you know we just have to keep going...'* (INT-12:273)

Participant 1, who was diagnosed with unexplained azoospermia, drew parallels between coping with infertility and bereavement. When asked how he was coping with his condition, he said:

*'...it's something that's already happened you didn't need to worrying about it because it's already happened...and I think let's just move on with it and I don't want to sit and stew on a subject... I mean yes the subject does bother me a lot but over the months, a bit like when you lose someone when you lose a granddad or a friend of the family after a while, it becomes a lot easier and it sits at the back of your mind a little bit...'* (INT-01:53).

He continued to say that he saw the interview with the researcher as a counselling session, because he felt that he was never offered to see a professional counsellor:

*'...to be honest the way I took this interview was pretty much a little bit like a counselling session. Someone who I could talk to about the whole subject, who I could ask questions, maybe stuff I never thought of before. I have never really been offered a counsellor as such...'* (INT-01:52).

Then he continued to say that he didn't particularly feel the need for a professional counselling session, because he felt that the support from his partner was all that he needed:

*'I didn't really particularly want one (a counselling session). It is something I need to come to grips to with myself and my partner... we have been really quite open with each other about it, we talk a lot about it that I don't really particularly need to have someone else to talk to. My partner is more than sufficient and we are a couple, we are really strong, so I don't think we need anyone else to talk to...'* (INT-01:53).

### **5.3 Perceived loss of masculinity**

A minority of men perceived the diagnosis of azoospermia as a loss of their ability to live up to traditional male gender role expectations. These men described experiencing loss of self-esteem and sense of their masculinity upon discovering their diagnosis.

Participant 11 explained that he felt less of a man and embarrassed about the diagnosis:

*'I've been embarrassed about it. I can't talk about it at work. Most of the people I work with are all blokes, and I am sure some of them will be understanding- most are parents as well. All got kids. So I felt failed in a way... the fact that everybody else has been able to have kids and I can't, I'm embarrassed to mention that because I feel that I don't like them to think there's something they can do that I can't. And that is one thing that they can do that I can't, and I feel less of a man because of that'* (INT-11: 81)

On further questioning on why he felt less of a man, he said:

*'Because there's not many jobs really that a man does in life that is your purpose as a bloke, but one of them is to help a woman conceive, you know? That is why men and women are put together, isn't it? So if I can't fulfil that part, my side of the deal, and you feel other blokes can, that's what makes me feel less of a bloke, really. I think it forms part of what, how you feel. If you feel masculine, that*

*forms part of it, you know, and not being able to, get a woman pregnant, sort of like dents the idea of how masculine you are, how you see yourself I don't feel fulfilled as a bloke. Probably in the same way that xxxx (my wife) may not feel fulfilled as a woman if she hasn't had kids' (INT-11: 83,129).*

In a similar tone, participant 14 explained that he felt less of a man when he found out that he could not reproduce:

*'Going down a stereotypical man route, I felt less of a man; I didn't think I was good enough or able enough for anything. A man would feel the fact that, he's put on this earth to be a man to then have children, and then children to evolve him and then go forth and such like. But then to be told that you've got no sperm, you've got this genetic syndrome which is no fault of your own, or your parents, you can't have children. I think it's just one of those stereotypical men things where, you think of all your friends have had children and your parents 'n everybody else has never had any problems and now unfortunately you've been left with the problem that you can't give your wife what she craves...it is difficult... So it is a bit difficult. It is difficult the fact that all my family and all my cousins have had children left right and centre and I'm the only one who genetically isn't correct in that respect, so yeah, it is hard, but in the last couple a months since I've known, I've learnt to live with It' (INT-14: 43, 129).*

The majority of men felt that the diagnosis did not have an impact on their sense of masculinity. The following quotes summarise the comments of some participants:

*'No, I don't think I felt any different in myself' (INT-04:67).*

*'I've never felt effeminate or anything like that or less of a man in that regard. I think a lot, I've thought about that quite a bit... I don't have any, erm, I don't have any problems with feeling masculine because I am quite blokeish at times, so no, that hasn't been an issue' (INT-02:103).*

*'It didn't really...it didn't really make me feel any less of a man or anything like that. I mean it's certainly nothing like I can help or I've done... because of that, I didn't see the point of letting something beyond my control kind of, you know, change the way I necessarily view about myself... in terms of actually feeling like a man, it's not really changed that' (INT-15:).*

## 5.4 Impact on relationships

Most participants admitted that their partners/wives were understanding following the diagnosis, gave them words of encouragement and supported them when going through treatment. In the majority of cases participants said that having a supportive partner was key in coping successfully with their problem. These men reported that going through this experience brought them closer together with their partner as a couple and made their relationship even stronger than before. They coped better by comforting each other, discussing treatment options together, and with responding appropriately to other's inquiry about their childless status. A few participants reported some friction with their partners following the diagnosis.

### 5.4.1 Situation brought partners closer together

One participant admitted that coming to the fertility clinic together with his partner helped their relationship to grow stronger and brought them closer together. He said:

*'...I think coming to the clinic has actually helped us as a couple because we've done it together. Every time we have been here practically we have been together so we have done it between us it's not just like all on me... my partner is really supportive ...'* (INT-01: 35).

On questioning whether the diagnosis of azoospermia had any effect on their relationship the majority of participants said that it did not have any effect:

*'It's brought us a bit closer together actually, erm you know, you go through this together we can pretty much go through anything...'* (INT-02:117).

*'It's brought us closer together to be quite honest. So we are now stronger than what we were originally because we've both sat down and worked out the next step sort of thing... so we're getting to get through it together'* (INT-03:85).

*'...you have your ups and downs and things happen in a relationship, but I wouldn't say that any of that had a direct effect to anything that went on in the relationship...and I certainly wouldn't say it affected anything'* (INT-08:105).

*'...it hasn't really affected the relationship if we still love each other, we still...doesn't stop us from doing things or going on holiday, but it's still... I mean, yes, there's something still missing, because as I told you before, where we come from, you know, children, it's like, you must have a child'* (INT-09:155).

#### **5.4.2 Conflict and negative impact on the relationship**

The diagnosis of azoospermia was a source of conflict for some couples. One participant explained that disagreement about the best way of treatment made his relationship difficult at times and created friction between the partners. His partner was also present during the interview.

*'We hold, I think it's fair to say, we hold slightly different views on what we should do next...so we've had some discussions about that and that's quite difficult if you hold different views on things' (INT-07:136).*

Another participant described how the diagnosis affected his relationship, especially with his wife knowing that he had been taking anabolic steroids for bodybuilding, which had contributed to his azoospermia:

*'...it had a big impact on our relationship. It made it quite hard...because it is something I have done (taking steroids), so I don't like to talk about it because I get embarrassed and I get very defensive, so she felt she couldn't talk to me. I tried not to talk about it. Even though she wanted to, I didn't want to talk about it because like I say, when it's about me, I don't want to talk about it, and because it was my fault, I didn't want to talk about it... I could talk about it for about five minutes and then I start getting angry and abrupt and then I'd close the conversation off which made her more upset...I felt like I couldn't talk to her, it was quite tense... it was constantly there, it was in our everyday life...' (INT-10: 43, 45, 103).*

He then continued to explain that the couples negative emotions were compounded following each unsuccessful attempt to conceive, each time his wife came on a period:

*'..she didn't toss things back in my face but at that time of the month, every time that part of the month came up (her period), it was a sad part of the month, it was the... it's not happening this month...and the disappointment hit and it was always like that for a couple of, a few days and then it was like, we've tried this month and obviously it still didn't happen, so it's getting quite difficult because we're both getting very disheartened and we're both thinking, 'are we ever going to be parents?', because that's all we want to be, is parents' (INT-10:45).*

### **5.4.3 Feeling guilty and wanted to leave the relationship.**

Several men felt that they were disappointing their partners/wives because they were unable to fulfil their desire to have children. Participant 2 explained of his initial disappointment when he found out about the diagnosis:

*'The first thought was my partner, because I think for a woman it's a lot more important to go through pregnancy and that, it's like, that's why we're here, to procreate and to carry on the species kind of thing. So you think, if you can't do that...it's quite difficult to comprehend. And also, I want kids too; I want to bring kids up and everything. So it's the idea 'that would be it'. It was quite daunting...'* (INT-02:75).

Three of the 15 men said that it crossed their mind to 'let their partner go' because they felt guilty that they couldn't give them what they really wanted and felt that they were letting them down. Participant 1 said:

*'...it made the relationship at that time impossible (cough)...I was trying, I admit, I was trying to push my partner away...it just really pushed us and I felt ridiculous. I thought at times it might be best if I left her and you know she could carry on and meet somebody and go like that...'* (INT-01:43, 118).

And continued...

*'...and I was trying to say look, 'you don't have to stay on board with me', but I was thinking 'if you do', plus I love her to bits, and I was thinking (it is not my fault), I was born like this anyway, so I was just trying to help her through it... as well and just we will do it together we will keep going I'll do whatever it takes... I think her mindset instead of thinking a little xxxx (his name) she's thinking I just want you to be the dad ... and that's what her mindset has changed to I think. I talked to her about that (leaving me if she wanted) and she said no, no, no, no. She says as long as you're there for me and the baby...So that reassured me somewhat'* (INT-01: 43, 69, 118).

Participants 9 and 11 also felt guilty and explained to their partner's that they were free to leave them if they wanted to find someone that could give them children:

*'When I told my wife though at the time, you know, I said well, I won't stand in her way if she, if she decides to leave. I won't stand in her way if she decides to, because we're not getting any younger, and with a woman the clock is ticking. I said well, you know what I mean, but my wife was never, ever blaming me to say well it is your fault I*

*don't have a child, no, nothing like that. So, I thank her for that, but I told her, I said well, I won't stop you if you want to go and marry somebody else or, I won't stand in your way because I can't give you, if I can give you what you want, I too want the same thing as well, but I can't give it to you. But no, she said no, we're in this together, we're both Christians, we believe in the word of God, we stand on the word of God, we have seen the miracles happen to family and friends who have been in similar situations as well' (INT-09:155).*

*'I did actually say to her, I said, if you really want children, if you left me because you want to have kids, I would accept that...because I feel like I'm the one that's letting the side down. So if she ever wanted to leave me for somebody to go and have kids- because she had a desire for children greater than (to be with me) [pause]... (I would have said) go with my blessing. I'd be heart broke, but I would fully understand, you know? But she says no, if I can't have kids with you then I'll not want them with anybody else. So in some ways that makes me feel worse, because she's sticking with me even though I cannot produce children for her' (INT-11: 143).*

#### **5.4.4 Communication between partners**

The diagnosis made communication between partners difficult for some couples. One participant explained that he found it very difficult to talk about the subject with his partner because they had disagreements as to what the best way for solving the problem and moving forward was:

*'We both probably come from families that that don't talk very openly, so you know, we each do a lot of thinking, ...we are fairly intelligent people so we know that we're both thinking deeply about things, and we're both coming to terms with how we feel about it...but we don't often just talk for talking's sake...we do occasionally talk about it and obviously we've got a lot of talking to do now that we have information about what to do next...but it can be uncomfortable obviously, especially if you hold different views on things' (INT-07:141).*

Participant 10, whose azoospermia was secondary to taking anabolic steroids for body building, explained how bringing the conversation up with his partner made them both become upset. So, they tried to avoid talking about the subject.

*'...it had a big impact on our relationship. It made it quite hard...because it is something I have done (taking steroids), so I don't like to talk about it because I get embarrassed and I get very defensive, so she felt she couldn't talk to me. I tried not to talk about it. Even though she wanted to, I didn't want to talk about it because like I*

*say, when it's about me, I don't want to talk about it, and because it was my fault, I didn't want to talk about it... I could talk about it for about five minutes and then I start getting angry and abrupt and then I'd close the conversation off which made her more upset...I felt like I couldn't talk to her, it was quite tense... it was constantly there, it was in our everyday life...' (INT-10: 43, 45, 103).*

#### **5.4.5 Effect on the sexual relationship**

A few men said that they were less happy with their sexual relationship following the diagnosis. These men explained that they engaged in sexual intercourse less frequently and they experienced low desire for sex. Some men said that it felt 'unnatural' because sex became a reminder of what they couldn't do, i.e. make their partner/wife pregnant.

Participant 10 said:

*'When it come to that time of the month (mid-cycle), we were like we've got to do it because we've got to do this and that, we've got to do it here, we've got to do it at this time, we can't miss it, it became like life was all about that and it made it, for me, it made it feel like we weren't having intercourse because we wanted to, it was because we had to. It didn't feel natural, you know, so it made things quite difficult...it affected me in a lot of ways that my wife doesn't understand... but she does understand because it's affecting her as well, as all she wants is a baby' (INT-10:45).*

Participant 7 said that he felt his wife became more distant and that the diagnosis posed a challenge to their relationship, which was an issue for him:

*'I think it's affected our relationship at home in terms of for instance just having sex, since it's become clear that it's my problem, we don't have sex as often as we used to. So that's an issue as well. For me that's an issue, I don't know if it's an issue for xxxx (my wife) because we probably haven't talked about it...because we got a lot on, a lot of thinking going on...' (INT-07:139).*

The majority of men however said that the diagnosis of azoospermia did not have any effect on their sex life. On questioning whether the diagnosis had an effect on his physical relationship, participant 2 said:

*'No, no. No we've got quite a healthy sex life' (INT-02: 111).*

## 5.5 Effect on everyday life and work

Participants described the impact the diagnosis had on their everyday life.

Participant 2 said that the thought of the diagnosis made him underperform at work, and participant 3 explained how the diagnosis changed his behaviour immediately after he found out, describing how he became more irritable.

*'I have been completely useless at work. I've been distracted; concentrating on things has been very difficult while you're going through it...'* (INT-02:101).

*'I became snappy, I didn't sleep properly, and when I was at work my head was just all over the place, I was making mistakes left, right and centre...'* INT-03:77).

Participant 10 described how he changed his habit of going to the gym after he discovered the diagnosis and the effect the anabolic steroids had on this:

*'It was when the doctors told me that what I was doing (taking anabolic steroids) was the reason (for the azoospermia), which made me stop, I stopped instantly. I chucked everything in the bin, got rid of every single protein shake, the cups, even down to the cups, the beakers to mix it in. I got rid of everything within five, ten minutes of coming home it was all gone, and even the gym, I quit the gym. So, I have been to the gym for a year. It (the diagnosis) had a big impact on me'* (INT-10:37).

## 5.6 Summary

All participants in this study shared the diagnosis with their partners/ wives. None of the participants stated that they felt rejected or blamed by their partner and /or family upon disclosing their condition to them. The majority of couples decided to inform their close family members of the diagnosis. Only a few chose to inform others beyond their close family members, including their work colleagues. Men in general were reluctant to disclose the diagnosis to colleagues at work, and if they had to, they avoided giving the true reason. Some couples decided to keep the news strictly to themselves. Participant's comments with regards to non-disclosure reflected the fact that there is still a degree of stigma attached to the diagnosis of male infertility.

Participants described a variety of ways that they found helpful when coping with the stress of infertility. They highlighted the importance of having a supportive partner and family around them. The majority reported that the best means of coping with

the diagnosis was their caring, understanding and supportive partner/wife. Only a minority of participants suggested that it would have been beneficial for them to receive psychotherapy from a professional counsellor.

The majority of men felt that the diagnosis of azoospermia did not have an impact on their sense of masculinity. Only a minority of men perceived the diagnosis as a loss of their ability to live up to traditional male gender role expectations. These men described experiencing loss of self-esteem and sense of their masculinity upon discovering their diagnosis.

Most participants admitted that their partners/wives understood following the diagnosis and gave them words of encouragement and supported them when going through treatment. The majority of men reported that going through this experience brought them closer together with their partner as a couple and made their relationship even stronger than before. A few participants reported a degree of friction with their partners following the diagnosis, which created conflict between them, and reported communication difficulties between them.

Several men felt that they disappointed their partners/wives because they were unable to fulfil their desire to have children. Some men wanted to 'let their partners go' because they felt guilty that they couldn't give them what they really wanted.

With regards to the effect on sexual relationships, a few men said that they were less happy with their sexual lives following the diagnosis. These men explained that they engaged in sexual intercourse less frequently and they experienced low desire for sex. Some men said that it felt 'unnatural' because sex became a reminder of what they couldn't do, i.e. make their partner/wife pregnant. The majority of men however said that the diagnosis of azoospermia did not have any effect on their sex life.

## Chapter 6: Decisions about fertility treatment

Men diagnosed with azoospermia faced the decision to undergo a sperm retrieval operation in order to try and recover sperm for fertility treatment. Another decision men and their partners were faced with was the option to use donor sperm for their treatment, if they decided not to have the operation or if the operation was unsuccessful in retrieving sperm. The aim of this chapter is to explore matters of importance to men and their partners about making these decisions.

### 6.1 The sperm retrieval operation

#### 6.1.1 *General feelings and thoughts about the operation*

Participants discussed the rationale behind the decision to undergo surgical sperm retrieval or not. Several participants were reluctant to have the operation because of the low chances of sperm recovery and concerns about possible short- and long-term side effects. They said that they felt nervous and found the whole experience ‘daunting’. When asked about his feelings to have an operation, one of the participants said:

*‘It’s a bit daunting. I have never really had an operation at all in my life and I don’t really like the idea of someone having to cut me open down there...definitely I’m nervous about it and I’m not looking forward to the fact that I know for a fine fact that I’m not gonna be able to walk (properly) for a while and I’ll not be able to drive anywhere or do anything’ (INT-01: 89).*

The same participant commented on how embarrassed he would have felt if his colleagues at work and friends found out the exact reason of why he was on sick leave. This once again highlighted the degree of stigma attached to the diagnosis of male infertility:

*‘...and people are going to be asking questions what is xxxx doing? Why is he not coming out? Why is he not answering my calls? He is off work but what is he doing? I was actually thinking about putting holidays in at work to cover this. I don’t go on the sick and my sickness record at work is impeccable but I don’t want to have people in the background asking questions or me having to try and explain to them’ (INT-01: 89).*

Participant 3 said that the idea of having a sperm-retrieval operation did not appeal to him because he had a fear of not waking up from the anaesthetic:

*'... well, the idea of having surgery didn't appeal to me to be honest with you...you worry about are you going to wake up from the anaesthetic, is something going to go wrong...'* (INT-03: 99).

Participant 11 explained how nervous he felt, because of the nature of the operation:

*'I was nervous about it, because you go in right to the heart of what should be a bloke's manhood, you know? Cutting right in there. But I was willing to do it'* (INT-11: 185).

### **6.1.2 Reasoning and decision making about the operation**

Participants were asked about the reasoning behind their decision to undergo an operation. Participants who decided to have the operation said that the main reason was to try and do everything possible in their power to get their own sperm, or at least to put a closure if sperm is not found. Some said that they were willing to take potential risks, despite knowing that the chances of sperm retrieval were very small.

*'The reason I went with the surgery, even though we weren't expecting anything from it was, as I said before, to make sure I've done everything I can, so I can say at the end of it that there is nothing more I can do...because you can stress about things that you can change, but there is no point stressing about something that is out of my hands. And that's made going for the donor a lot easier because, that is the way it is and we are grateful there is a donor option after that'* (INT-02:69, 141).

*'I was quite a willing participant in so much as it's an opportunity, it's a chance, you know. I can't do it the conventional way and there is an opportunity to try doing it non-conventionally... I was more than happy to, to go through with it, the procedure, and take that chance'* (INT-11: 185).

*'I got offered this chance, and had to take it, it was like if we don't take this, I'll always be thinking, what if I had that operation? and what if they found sperm, so I thought, it's a must, you've got to do it'* (INT-12: 149).

*'So, all I kept thinking of is...I can do everything within my power, if it all fails I can sleep at night knowing that I did everything I could...and that... that was always in my head, I thought, if I was to say no I'm not doing that, not down there, no chance. I would always have it in my*

*mind that I could have done this...and what if, what if that had worked? Now I can sleep at night knowing that I've- I've- up to now, I've done everything I could...' (INT-13: 473, 476,485).*

Participant 8's comments expressed his very strong desire and desperation to be a biological father:

*'I was basically willing to do anything I possibly could to be a biological father. You know if somebody said, 'If you jump off that bridge, you can, you can have some sperm', I would have jumped off a bridge. You know what I mean. Not, not out of desperation, just because that's to me, the way forward, you know' (INT-08:95).*

Participant 3, whose azoospermia was unexplained, said that he wanted to have the operation in order to try and find out a reason for his azoospermia.

*'I knew having the operation would solve the mystery' (INT-03: 99).*

### **6.1.3 Fear of potential complications and side effects**

The majority of men expressed concerns about the potential surgical complications and side effects of the operation. This was one of the main considerations when deciding to have or not to have the operative procedure for sperm recovery. Low testosterone levels and related side effects came across as one of the major worries that men had with regards to long term effects of the operation. This is highlighted in the comments of three participants below.

*'I was concerned about the risks, about like bleeding and shrinkage and testosterone... that was a major kind of worry the testosterone level... you can lose your testosterone hormone so you would have to have tablets to stay, like healthy, as, as it would. So that was a worry, because I didn't want to start turning into a woman [laughs]...' (INT-12: 153).*

*'I mean, I was told that it (the operation) could potentially have effects on testosterone levels, which in my case is quite low anyway, which could have a knock on effect to my future health...the surgery itself has implications or the possibility of infection and this kind of thing, well they're relatively small, but for it to have a long term effect on my health is a worry and that's a risk, so I'd have to think very, very hard about that' (INT-07:169).*

Participant 11, who was interviewed following the operation said:

*'I had two concerns. The first one is that it (the low testosterone) would dent me sexual appetite, which it hasn't, and the other one was the amount of pain I might suffer afterwards, just physical pain from the operation. Other than that, no other concerns really'* (INT-11: 187).

Concern about potential surgical complications was another reason for being reluctant to have surgery. Several participants said that they weighted the chance of finding sperm, and having a successful pregnancy from it, against the potential complications. Participant 14 decided not to undergo an operation because of the risk of potential complications that could affect his future life and the chance of finding sperm was very small:

*'...there was a small chance that there was something (sperm) there, possibly, but not guaranteed... if there had been a bigger chance, then no doubt I would have gone for it...but then, I was given a list as long as me arm of side effects, of what could happen to myself in later life...and I didn't like the list of side effects, so that was my decision (not to have the sperm retrieval operation)..'* (INT-14: 117).

#### **6.1.4 Partner's influence on decision to have an operation**

Some participants said that their partners had a strong influence on their decision to undergo an operation. Some women were keen for their partners to have the operation and some were not.

Participant 7, who was undecided at the time of the interview, said that he wasn't keen to have the operation. He came across as being under pressure from his wife to undergo the procedure. His wife was not present during the discussion. He explained the reasoning why his wife wanted him to have the operation and why he was reluctant.

*'...she would rather this would be a product of both of us and therefore she is more keen for me to look at the surgery option... whereas I have to say my view is much more to maximise our chances, which would mean avoid (the operation) and minimising the risks as well, which would mean avoiding a surgery which is likely not to be very successful anyway, and potentially going down the sperm donor route, which would maximise the overall chances of it working'* (INT-07:153-155).

He then continued to re-enforce his intention not to have the operation.

*'I'm not that keen, bottom line, it's an unnecessary operation. I am very keen on operations which are essential for saving life and improving quality of life, but this isn't, for me, an essential operation, the risks I am told are significant...there are risks involved and again, the likelihood of success I am told is quite low. So I'm for that reason I am not hugely in favour of it right now'* (INT-07: 156).

On the other hand, participant 14 explained how his wife did not put any pressure on him to have the operation:

*'She didn't want me to go for the operation for that main reason (the potential side effects), the possibility of me being affected in any sort of way, in later life...my wife doesn't want anything to happen to me, and to go down the route of an operation for a miniscule opportunity of having possible sperm in there, to not having any at all, she was behind my decision. It was mainly her decision, because I was going to... I was actually getting my head around doing it (the operation), and she said look, at the end a the day, we've got a very, very small chance of having anything (any sperm), and the chance is minuscule, and even the doctor said it was minuscule, but it would be your decision...and that made it for me, I thought well, if it was a big, big chance, anything from forty to fifty percent, I would have done it'* (INT-14: 117).

Participant 15 explained how his decision to have the operation was dominated by his wife's views:

*'...it's me having the operation and everything, but I probably had little say in it to be honest. Obviously you know, my wife, she obviously wants me to have it. I mean, I would do too...but no one wants an operation, and especially in that area, to be honest it is terrifying to think of the actual process... but I think what makes it worse is the fact that the odds are quite low as well. It's certainly not something I'm looking forward to really'* (INT-15: 85).

And he continued to say that he wouldn't have chosen to have the operation if he wasn't pressurised by his wife:

*'To be honest with you, if it was down to me, I personally probably wouldn't go through with it, but I'm part of a relationship here, so I have to obviously take into effect what my wife feels and everything. So, I'm kind of doing it for her in a way really'* (INT-15: 85).

Participant 2 explained that his wife wanted him to have the operation because of her desire to have his child.

*'She didn't like the idea of using donor sperm at all at first, she very definitely wanted me to go through the operation to see that chance... she wanted to have my child' (INT-02: 159).*

## **6.2 Attitudes and feelings of participants towards using donor sperm**

This section describes the considerations of the participants when deciding about the use of donor sperm for their treatment. At the time of the interviews, 14 out of 15 men in this study were faced with the decision to use donor sperm for treatment, either as a back-up option in case the sperm-retrieval operation was not successful, or as an alternative to undergoing a sperm-retrieval operation. Participants were invited to comment on how they felt and what influenced their decision to use or not to use donor sperm.

### **6.2.1 General considerations and issues about the use of donor sperm**

The following quotes describe some of the thoughts and concerns of participants with regards to the use of donor sperm for treatment. A common theme that emerged was the attempt to rationalise the use of donor sperm by comparing it to the idea of having to bring up foster children.

Participant 14 tried to explain how he would feel about bringing up a child resulting from the use of donor sperm:

*'At the end of the day, I've got a friend of mine whose got two children, and the first of them is not his. He had that baby since two months old since the natural father walked out, and that child calls him dad. So for me, I look at him as a role model, even though he's got his own children. The fact he can bring up another person's child and call it 'my son'. Then obviously for me, even though it would be part of my wife, then it technically will be my son or my daughter or how you want to call it, but positives on that note, but personally, still, I don't think about it all day every day, but the occasional time when you see somebody walk down the street with a baby 'n the odd television programme has babies on it, I do think about it' (INT-14: 43).*

When asked how he felt about the use of donor sperm, participant 2 said:

*'I looked up azoospermia (online) basically and then obviously you realise your options are very, very limited at that point. So at that point I started thinking that a donor would be... (a possibility) and how I felt about that, you know, you put an idea in your head and you work through it to see what came out... I thought that if I met xxxx (his wife) after she'd had children and everything went as it did, and I was there to bring up these kids, would it make any difference to me? And it wouldn't. So that's, how it went through in my head. I'd have no problem doing that. That's how it is'* (INT-01: 153).

He continued to say that he felt 'strange' when donor sperm was first mentioned at the fertility centre:

*'When the nurse was going through the options with us, it was the bit that, that I found the strangest, to be honest with you. I mean, specifically when they bring out the donor lists and it says the occupation and, you know, the characteristics was very, very strange for me...'* (INT-02: 147).

When he was asked to explain why the whole experience felt strange, he said:

*'Because it makes it, turns it from something that's you know a medical thing into something that's personal. It's personalising something and, and it puts in your head that there's somebody out there whose DNA, you know, I'm going to be bringing up a child ...that was quite strange'* (INT-02: 151).

And he continued to express some concerns about the possibility of meeting the donor face to face in the future:

*'...I am now very interested in nurture versus nature, and I don't think we're going to have any problems at all. I'm not worried about anything. But the, seeing the bit of paper with the donor details on, was very surreal. It was quite strange. I found it weird. I mean, the thing that's gone through my head since then is imagine sitting in a pub with the guy (the donor), you know, saying 'hello', that would be possibly the strangest thing I could think of...'* (INT-02: 151).

Participant 2 said that his decision to have a sperm retrieval operation made the subsequent decision to use donor sperm easier, because he felt that he did everything he could to get his own sperm, and after the unsuccessful operation, he felt that he felt grateful that the option of donor sperm was available.

*'Having the operation, which we weren't expecting anything from, it was a way to say I've done everything I can, and that's made going for the donor a lot easier because, that is the way it is, and we're grateful*

*there is a donor option after that. So that's made it easier, if I didn't go for the operation I would always have that bit in my head which was, you know, what if, what if I could have lost an opportunity, so, I've got no regret' (INT-02:69).*

Participant 2 explained that the most important factor in deciding about the use of donor sperm was his wife's desire to carry the pregnancy:

*'...at that point, it was just this is the options we've got, you know, that's we can either not have children or we can go through this (use of donor sperm) or we can try adoption. The biggest factor for me in that was my partner, she, you know, she wanted to get pregnant; she wanted to go through that whole thing. So that was, that was important for me as well...' (INT-02: 155-157).*

Participant 5, who was fine about using donor sperm commented:

*'I'm fine with it, I mean, it might not be mine but at least it is going to be part of xxxx (my wife) and I can bring it up, I mean I've got that much love to give it, I'd like to do it'' (INT-05: 145).*

When asked how he felt about using donor sperm, Participant 1 said:

*'It's our baby, even it's half a one like mine and you know like it's fully xxxx's (his partner's) and then someone else's, but it's our baby do you know what I mean? I think it's something I gotta come to terms with but I think as long as it's like our daughter or our son I think we are going to be fine to be honest' (INT-01:69).*

## **6.2.2 Other factor consideration in decision-making about using donor sperm**

### **6.2.2.1 Nurture vs Nature and disclosure of donor identity**

Another theme that emerged from the interviews was the concern about genetic differences between the man and his future children, and also the use of a 'stranger's' sperm and the disclosure of donor identity.

Participant 8 explained the importance to him of being a good parent as compared to being a biological father, when deciding to use donor sperm.

*'...you won't be the biological father but I don't think being the biological father is the be all and all. You know, I think it's about being a good parent and looking after the child and doing the very best for*

*them. And, you see a lot, I see a lot a people who even though they are biological parents are absolutely terrible parents. Biological fathers but terrible parents. So I don't, I don't really put that much faith in being the biological father to being the parent. You know what I mean...and I'm looking forward to the next steps of treatment, I am obviously on a waiting list at the moment... we're looking forward to that coming to the point where you can one day have a family. I would love for it to be a different way, but it's the way it goes'* (INT-08: 89, 113).

On questioning what went through his mind when considering donor sperm treatment, Participant 4 said that one of his worries was the lack of genetic relation to his future children, and also fear of reflection:

*'...I am not going to see myself in them (children) or any children that come as a result of the fertility treatment (using donor sperm) ... I know that I've got personality traits in my dad, from my dad...I don't know how genetic that is, and I appreciate nature versus nurture and all the rest of it, but I know I'm very much like my dad and I was projecting on that, onto the idea of having donor sperm and a child that would not necessarily be biologically me and how I would potentially bond with that child...or would, in the same way that I wanted to do computing, like my dad, would the child want to do things that I wanted to do?...and if I was to tell them, I am not really biologically yours, is that going to be a big thing for them? And would they use that against me? So and I had ideas of, you know, would they just turn around and say, 'Well you're not my real dad, I am gonna talk to my mum'* (INT-04: 59).

#### **6.2.2.2 Donor anonymity**

One participant commented on donor anonymity. Participant 4 said that he did not object to the idea of disclosing this fact to his child if conceived from donor sperm. He said that one of the reasons for this was the importance of the child's right to have access to his/her genetic history. His comments were:

*'...I appreciate they've got the right to know where they came from and I probably would never hold that information from them, I would probably, from xxxx (my wife) and my own viewpoint, we would tell them all the way through their life that they were special and they were different and that there, you know, there was somebody else and my reasons for wanting to tell them is that I believe that if there was*

*medical problem and or anything and they wanted to ask me questions and maybe there was medical problem or a genetic issue that we don't know about and things like that'* (INT-04: 3).

However, he continued to express some concerns about the lack of donor anonymity and that he was uncomfortable about the idea of donor identity disclosure:

*'...Basically xxxx (my partner) had watched during the time we were going through the treatment some TV programme, either channel five or channel four, and it was about sperm donor children finding their donors...I just didn't like the fact that at eighteen... the fact that they could just go off and quite easily find their donor...but that TV program scared me....'* (INT-04: 3).

On questioning why this idea 'scared' him he said that one concern was fear of rejection by the child when finding out who his biological father was and the possibility of him and his wife meeting the actual sperm donor face to face:

*'... I think in my own mind I had this idea that they'd want to go and see them and then as a spotty seventeen year old and try and go and move in with them and say, 'ah well, you don't count anymore' and I think that is probably one concern'* (INT-04: 3) .

*'...So it wouldn't come necessarily as a shock, but I think, I think I'd be concerned of coming face to face with that donor and I think certainly xxxx (my wife) would become concerned about the child, you know, and saying, 'oh this is my biological dad that you've never met', but you had the child, and it scared me, and that's probably another reason why the donor side of things seemed even more scary...'* (INT-04: 3).

### **6.2.2.3      *The importance of external appearance and resemblance to parent's personality traits***

Appearance and resemblance to the father was one of the most important factors considered by participants and their partners when deciding whether to use donor sperm. All participants said that they wanted to be fathers but they also wanted to look at their children and 'see themselves in them', even though they knew they were not genetically related to them. As such, one of the most important factors taken into consideration when choosing a donor was the donor's physical characteristics.

Participant 5 highlighted that external appearance was the most important factor when considering choosing a donor:

*'...I think I could take a donor of someone that looked like me... like hair colour, eye colour etcetera...apart from import foreign sperm' (INT-05:156).*

Participant 8 commended about people's comments with regards to the resemblance of baby's characteristics to the parents, and how he would feel about knowing deep inside that there is not genetic link between him and his child. He said:

*'I think it's going to be quite difficult when I actually become a parent...you know when a child is born and people say so it looks like their dad or it looks like their mum... and somebody will say, 'Oh, it looks like you', and in your mind you're thinking, 'It doesn't, it doesn't at all', but people look and make similarities, they look at a child and say, 'Oh, it looks like the mum, it looks like the dad', because it is from the mum and dad. But when people say it to me, I will have to say 'Oh yeah he does', and know in my heart that I am lying out my back teeth, but what do you do? You are not going to say, 'oh by the way, no, it's not mine', you are just going to go along with it' (INT-08: 113).*

Participant 13 also highlighted that appearance was his main concern when it came to considering the donor option:

*'For me, I think it's, it used to be, and it still is a little, of what the child would look like. I mean, you've got your obvious, if it was black for example, do you know what I mean, or slightly black. Ginger, you know, they're the two main things. Ginger and obviously coloured or whatever They're simple things... but you hear these horror stories, don't you? If we're to go through donor I would obviously, I'd love a boy. But I think because it would be a donor, I would prefer a girl to look like me wife...' (INT-13:227).*

Participant 9, who was of black African origin, commented on the desire for the baby to be of the same 'colour' as the father and once again highlighted the importance of external characteristics of the chosen donor. He explained of the difficulty of finding a donor of the same ethnic origin, due to limited availability of sperm donors in the region. When asked what his considerations were when choosing a donor he said:

*'Well, obviously we wanted the person to be at least African, at least, I mean, we don't want a child that would be white [laughs]. Not that I have anything against white, obviously, but because, how do you explain that? [laughs]. You know what I mean? ...or a mixed race child, how will you explain a mixed race child...so that was another challenge as well because there wasn't that many Africans on the (donor) books' (INT-09:167).*

Another interviewee highlighted the importance of the appearance of the child to the parents, and therefore express the desire to have a baby girl, which was more likely to look like his wife, rather than a boy that was likely to resemble the sperm donor in appearance:

*'For me (the worry) it still is a little, of what the child would look like. I think you've got your obvious, if it was black for example [laughs], or ginger... it's simple things, just the appearance. If we're to go through donor I would obviously, I'd love a boy. But I think because it would be a donor, I would prefer a girl to look like my wife...'* (INT-13:227).

And continued:

*'We had been looking at the European sperm bank... we both talked about this and there was one (donor) on there that was a closest match, I mean we don't know what this person looked like, but it was more or less the same blood, hair colour, eye colour, height...but they were German. And you start to think, will they have a certain look? And then, the same as Danish and different nationalities, you start thinking have they got that kind of look? You know, and then you think, you don't want everyone to not think it's mine. That's the whole problem'* (INT-13:275).

Another participant commented on his wife's concerns about the appearance of the donor:

*'...I think she got worried about what sort of nationality, skin type, hair type...all these different things wouldn't look anything at all like me in any way, shape or form. She wouldn't have seen anything in her child with any resemblance to me whatsoever; any sort of donated sperm doesn't guarantee you that at all. To go to the European sperm bank and get a European looking person as opposed to more of an English character coming out...I think that put her off'* (INT-11: 155).

Participant 1 suggested using his brother as a sperm donor, because he would have been the closest resemblance to him, but his partner objected saying that she wanted someone they both did not know.

*'Me and xxxx (his girlfriend) were thinking maybe if we could pick someone that we both knew who was a bit like me...I mean I've got my brother as well and I was thinking maybe I could even ask my brother I was thinking, because that would be the closest. But, she*

*was like dead against that she was just like 'no if it's gonna be donor sperm it's gonna be someone that we both don't know' and that was pretty much the end of that' (INT-01: 84).*

When he was asked why his girlfriend felt that they shouldn't use his brother as a donor, he said:

*'I think she feels weird about it. She hasn't really said a lot about it to be honest with you, but certain things she was giving away like we don't want to be having a baby and looking at my brother every time my brother comes round, so that is the one thing as long as we don't know who it is. But she said she we both have come to this point and we're not going to turn around now, but we are worrying about other things at the minute and just putting this to the back of our mind until we hear something from the centre about an appointment maybe next year' (INT-01:84).*

One participant who wasn't keen on using donor sperm for treatment, appeared less enthusiastic during the search for a suitable sperm donor:

*'I was probably less enthusiastic, but I just couldn't push myself to be able to be as excited about moving on as xxxx (my wife) was, and that's why I think she took more of the role of looking online for donors. She obviously consulted with me, it's not as if she did everything and then said, over to you and do it, just find something. It was a decision and she went specifically looking for traits of me in people of my family in all of the different things we could search on. And we eventually found somebody that we felt was good enough to be a substitute in that situation' (INT-04:69).*

#### **6.2.2.4 Fear of relationship breakdown**

Two themes emerged with regards to the fear of either partner terminating the relationship. One theme was the fear of the male partner that his wife/partner would leave him because he could not make her pregnant and the second theme was the reciprocal concern of the female partner that her husband/partner will leave her, because he might see the resultant child conceived from donor sperm as not his own. These two themes are reflected in the quotes that follow.

##### **6.2.2.4.1 Men fearing that their partner will leave the relationship**

One participant said that his decision to use donor sperm was influenced by his fear that his partner might leave him for somebody else, so that was one of the reasons

he suggested the use of donor sperm, in order to give his partner what she really wanted.

*'But then I thought, she is gonna go off with someone else because I can't give her a baby, so that went through my head and then that's when I said about, like using a donor, you know, and I'd grit me teeth at one, you know, but like, if I had to, I would still bring it up like it was mine anyway, I am not going to know that person. We're both never going to see that person'* (INT-10:99).

#### **6.2.2.4.2 Women fearing that their partner will leave the relationship**

On the other hand, some female partners expressed concerns that their male counterparts might leave them because they might not see the children as their own. Participant 13's wife, who was present during the interview, said that she was worried of the possibility her husband leaving her because the resultant child from a sperm donor wasn't his.

*'We went through a lot of talking and I was worried about...it's hard really trying to explain. I think I was worried, what if he rejects it because he'll think it's not his child? You know, those kind of things we had to talk about. It's took us a lot, a lot of talking really, hasn't it?'* (INT/P-13: 222).

Participant 11 explained how some discussions he had with his wife before they got together influenced their decision subsequently on whether to have donor sperm or not. This is because his wife was thinking that he might not see the child as his own.

*'xxx (his wife) was a bit sceptical because she felt that it was like having somebody else's baby, which brings in the 'if she don't have children with me then she don't want children'. So she was partly thinking that it wouldn't be mine, it would be hers and somebody else's. And I think that bothered her...but a think what is in her mind is that, having sperm from somebody else, from a donor, it's basically like her having somebody else's child, and she was worried that I wouldn't see it as my child as well...so she was thinking I wouldn't be the devoted father that she would hope for, that I might sort of have a sense of rejection and that... 'it's your child not mine, you look after it', all this kind, you know, all the different scenarios, it's probably gone round in her head what life might be like if she had a donor'* (INT-11: 149).

*And he continued to elaborate a bit more on why his wife would be thinking that way:*

*'...this was probably based on stuff I'd said(before)... because when we first met, we used to work together before we started going out, and obviously you talk about different things and one thing that I said is personally I don't think I could bring up somebody else's child. But what I meant by that is, if somebody's already got children , I don't think I would have moved in with them to have a relationship and take up the raising of somebody else's children. I explained to her that I would see it as me own child, but she said 'but it won't be a part of you in there'. I said, well there would, really, I said being a father is a different concept to meeting somebody who's already got children...but whether she's taken that on board or not, I don't know.'* (INT-11: 149)

Participant 8's wife also highlighted her fear of rejection by her husband if they decided to use donor sperm. She said during the interview:

*'It was hard at first for me because I thought...how would xxxx feel about it? He is completely OK about it, but at first I thought, is he just saying that to make me happy..., we went through a lot a talking and I was worried about... it's hard really trying to explain. I think I was worried, what if he rejects it because he will think it's not his child? Those kinds of things we had to talk about and it took a lot of talking really, hasn't it' (INT/P-13:224).*

#### **6.2.2.5 Female partner's thoughts on using donor sperm**

This section describes the thoughts of some participant's partners with regards to using donor sperm.

When Participant 2 was asked about his partner's thoughts of using donor sperm he explained that initially she did not want to use that option and that she wanted him to have the operation in order to exhaust all possibilities of using his sperm for treatment:

*'She thought the idea was unpalatable at first. She didn't like the idea of that at all at first...she very definitely wanted me to go through the operation, see wanted that chance to have my child' (INT-02:159).*

He then explained how he tried to persuade his partner to accept the use of donor sperm as a backup, in case the operation was not successful:

*'We talked about that quite a bit and it took a lot of persuading with her...telling her that kids growing up, they will be seen as my kids, so I think I persuaded her in the end that I was happy with it...which I think*

*was important for her as well. You know, because she has fears now of me, or she did briefly, you know, me running away' (INT-02:163).*

Another participant's wife was reluctant to use donor sperm for the reason that she wanted the baby to be biologically her husband's:

*'I'm much more open to that thought (of using donor sperm) than xxxx (my wife) is. My wife thinks that if we're going to try any invasive treatment, let's say, the ideal is that it would be an operation on my part and IVF on her part and the baby would be ours...she's not so keen, she would rather this would be a product of both of us and therefore she is more keen for me to look at the surgery option first' (INT-07:153-155).*

Participant 6's wife was reluctant to use donor sperm, and was more comfortable with adoption, as compared to using donor sperm:

*'I asked xxxx (my wife) if she wanted to, you know, experience pregnancy and whatever... and she just sort of turned around and says well... there's adoption, yeah' (INT-06: 169).*

His partner, who was present at the interview added:

*'...it's a hard decision to make, you know, whether, you sort of consider IVF, you consider sperm donor, you consider adoption...'* (INT-06:39).

On further questioning, she did not elaborate any further on the reasons as to why she was reluctant to accept the use donor sperm. This couple decided not to use donor sperm for treatment at the end.

Another participant said that his wife was not keen on using donor sperm for treatment, but because of her advancing age, they were under time pressure to have treatment and therefore they decided to use donor sperm as a back-up.

*'My wife wants a child, yes, ideally she wants to rather have it from me, obviously...but if not, then, then yeah, we will go for it (use donor sperm). Not that she was excited about it, no doubt about it, she wasn't excited about the idea. But, as I said, time was against us and the pressure was on, the pressure was really one' (INT-09: 175).*

### 6.2.2.6 *External influences in decision-making about using donor sperm*

A number of participants said that they discussed the use of donor sperm with their close family members. A minority kept their decision to use donor sperm between themselves.

Participant 5 said that they fully discussed the option of using donor sperm with their parents and they had their full support.

*'... (We discussed it with) my parents. My mum and dad' (INT-05:162).*

*'Yeah, our parents. And they are one hundred percent supportive of whatever we choose' (INT/P-05:164).*

The following participants said that they discussed the use of donor sperm to very close family members:

*'I never mentioned it to anyone (outside our family). Well, we mentioned it to her mum, and her mum told her to stop being silly, and just wait and see what happens and that's like your last chance branch, that's the last think we need to think about because she said if you continue thinking like down these roads, it's never going to happen. So, she told her to stop being silly and focus on us, focus on what was happening around weh and it'll happen, when it's meant to. Hence, we're just trying to focus on us now and see what happen' (INT-10:123).*

*'She discussed it with her mother. See she told her mother that she's rejected donor sperm and why she rejected it, but, you know, there's only one person (donor available) in the area and she wasn't sure about the European sperm bank at all. So she did discuss it with her mother, but that's about it. The pair of us hasn't discussed it with anybody else' (INT-11:159).*

*'She told her mum, and her mum's partner. I told my mum and my mum's partner. I told them but I wasn't like looking for advice off them or anything, you know, my mother was supportive really, supportive about it, just dead supportive; (she said) 'there is plenty people out there like step dads and that and what have you' and it's just not an issue, sort a thing' (INT-12:181).*

Participant 15 explained that he had to tell his father, who was going to be the sperm donor:

*'The donor is actually going to be my father. So obviously I had to include him in it (the decision). But it all hinged on whether he wanted to do this in the first place. And he did, without a question. He said he was honoured that we asked and everything' (INT-15: 95).*

Some couples said that they never disclosed the decision to use donor sperm and kept it to themselves. Participant 2 said that the decision to use donor sperm was a private one, and that they did not discuss it with anyone else. They felt that the donor counselling session at the fertility centre was informative enough and that they did not want to disclose this to anyone external.

*'...we spoke to each other together; we didn't speak to anyone else about that decision. I think that's quite a private decision you make... I am not sure what other people do, but I mean the nurse was very helpful there, the donor counsellor and she was very helpful... cos there's, there are obviously questions, it's not something you ever think about and she pointed us into the kind of questions we want to be thinking about. You know, what happens when they're eighteen and how would you feel when they want to go off and find the donor, that's kind of weird to think about' (INT-02:163).*

Participant 3 explained that they did not have any external influence in making the decision to use donor sperm. When asked if they decided to talk to anyone else in order to help them make that decision, he said:

*'No, it was just mine and her decision' (INT-03:119).*

Couple 13 did not disclose the use of donor sperm to anyone. One of their concerns was that they will be 'judged' and they were worried that they may receive inappropriate comments from people that found out. When the couple were asked if they disclosed the potential to use donor sperm to anyone else, they said:

*'No, we've never mentioned it, not the donor bit. Everything else but not the actual donor bit' (INT-13:280).*

And when asked why they did not disclose it, they said:

*'You don't want to be judged really, you know, you want to just think that's our little family we've had, and we've been through all this procedures and we've managed to have this family. You know, and I think you just don't want to feel judged' (INT-13: 284).*

*'From my point of view, I feel too many people are ignorant to it. I know people that would, if they knew about the donor situation, I know people that in the family and friends that would come out with insensitive things; 'Ah, so what does- have you seen a picture of what the dad looks like?' I know people would say that. Tell me 'Who is the dad?', and then I'd feel this big, you know. It could lead to family fall outs on simple, ignorant comments. Just uneducated comments on the whole process' (INT-13:289).*

*'Yeah, it can be hurtful. I think people that just had kids naturally and knowing what we've been through for fourteen year, they wouldn't realise that would maybes hurt us, little things. Just things like that' (INT/P-13:297).*

### **6.3 Summary**

Several participants said that they were reluctant to have the operation because of the low chances of sperm recovery and concerns about possible short- and long-term side effects. They said that they felt nervous and found the whole experience 'daunting'. Some participants commented on how embarrassed they would have felt if colleagues at work and friends found out about the sperm retrieval operation.

Participants who decided to have the operation said that the main reason was to try and do everything possible in their power to get their own sperm, or at least to put a closure, if sperm is not found. The majority of men expressed concerns about the potential surgical complications and side effects of the operation but they were willing to take potential risks, despite knowing that the chances of sperm retrieval were very small. Some participants said that their partners had a strong influence on their decision to undergo an operation. Some partners/wives were keen for their partners to have the operation and some were not.

When deciding about the use of donor sperm, a common theme that emerged was the attempt to rationalise donor sperm use with the idea of having to bring up foster children. The possibility of donor sperm use created the fear amongst some couples that either partner might leave the relationship. One theme that emerged was the fear of the male partner that his wife/partner would leave him because he could not make her pregnant. Another theme was the reciprocal concern of the female partner that her husband/partner will leave her, because he might see the resultant child conceived from donor sperm as not his own.

The most important factor taken into consideration when choosing a donor was the donor's physical appearance and resemblance to the father. All participants said that they wanted to be fathers but they also wanted to look at their children and 'see themselves in them', even though they knew they were not genetically related to them.

## **Chapter 7. Discussion of key findings and conclusions**

Since the introduction of infertility treatments, the literature has been largely dominated by research dealing with various aspects of infertility diagnosis and treatment from the woman's perspective. This study aimed at providing a better understanding of the experiences and reflections of men diagnosed with their own infertility, a subject that has been relatively silent in the available literature over the past 20 years (Culley et al., 2013), for reasons discussed in more detail in the literature review. It used careful analysis of qualitative data to explore patterns in people's accounts of their experiences. The aim was to progress our understanding of the experience of male infertility, in order to improve the care provided to these men.

The male's experience in the therapeutic process of infertility is the focus of the discussion in the next parts of this chapter, which is based on observations and qualitative interviews aiming to capture the experiences of azoospermic men attending a tertiary fertility centre. This chapter discusses the findings of the study and draws comparisons with the current literature. An interpretation of the results is presented, with discussion of the clinical implications, the limitations of the study, and suggestions for future directions and research.

### **7.1 Interpretation of findings**

This section provides an overview of the findings for each theme that emerged from the fifteen interviews, and compares them to existing literature.

#### **7.1.1 *The men and the interviews***

This qualitative interview enquiry was a useful way of acquiring data and in-depth insights into what is important to patients, when it comes to the diagnosis and treatment of male infertility. This information helped identify specific strengths and weaknesses of the care we provide to our patients, and will hopefully drive patient-centred care provision improvements, discussed later in this chapter, that will improve the experience of infertile men and couples attending infertility clinics.

All men interviewed in this study appeared honest, open and forthcoming about their experience of being diagnosed with azoospermia, and provided detailed information about their reaction to the diagnosis and how it affected them emotionally and in their day to day lives. Most men said that speaking about their experiences to the interviewer was very useful. Some of the men appeared anxious at the beginning of

the interviews, mainly because they did not know what to expect, but as the interviews progressed, these men opened up and relaxed more. One man in particular said that it was helpful for him to talk about his experiences because he could express himself and 'let it all out.' Talking to a male interviewer could have influenced the gathering of data in a positive way, as men could have been more comfortable and open to talk about a 'male' subject to a man. Male infertility is a very sensitive subject and it would be interesting to examine whether different findings emerge if a female interviewer interviews male patients. Some authors suggest that gender dynamics can influence data gathering in qualitative research (Santovec, 2014, Pini, 2005). As discussed in Chapter 3, the fact that the interviewer was partly involved in the care of the interviewees was probably a more important issue than the gendered context. All men that took part in this study said that they found it useful that someone took the time to talk to them about their condition, and conduct research, in order to help them and others in the same situation. Men stated that they were interested in learning more about their condition and how it affects others. None of the participants had any bad experiences during their interviews with the interviewer, and none of the interviews triggered significant emotional upset.

### ***7.1.2 Reflection on my role as a qualitative interviewer***

With regards to my own experience in conducting this research study, I was quite familiar with the subject of male factor infertility but a novice in conducting qualitative interviews for this purpose. I was aware of the sensitivity of the topic and about the level of discomfort that could be elicited when discussing the participant's experiences. I was worried initially not to miss anything from the topic guide but this worry diminished with time as I became more familiar with the interview process and conducted more interviews.

As a healthcare professional directly involved with the care of infertile couples, I was familiar with the process of investigation and treatment related to infertility. I was particularly surprised by the number of individuals who were interested in participating in this study, and I did not have any problems with recruiting the target number of patients in a short period of time. I was also surprised how open and forthcoming individuals and couples were in sharing their experiences. There were moments when I was emotionally moved by the participant's experiences. I was sometimes touched and humbled by the participants' illuminating and heartfelt stories.

I was aware that identifying my professional role as a doctor could potentially influence my interaction with the participants and the qualitative information shared. My involvement directly or indirectly with the participants' clinical care and my medical knowledge and experience had the potential to affect the relationship with the participant and obfuscate the purpose of the research interview. Moreover, participants may have felt compelled to participate, fearing that refusal may jeopardize their care and they might have been reluctant to express views that were more critical of healthcare professionals.

I occasionally found it difficult to maintain my primary role as a researcher within the context of the interview. Occasionally the participants attempted to change the focus of the interview towards their clinical concerns. This could move the conversation from my directed data collection questions to participants' requests for answers to medically-related questions. In order to avoid this, I always emphasized my role as a researcher at the beginning of the interview and I asked the participants to defer any requests for medical information until the end of the interview. I strived to maintain a professional, yet comfortable and warm attitude throughout the interview process.

On the other hand, my role as a doctor and my background experience of interacting with patients helped me to quickly establish rapport during the initial contact. This in turn helped to build trust, which was essential in order for participants to share with me intimate details about private and often very sensitive areas of their lives. I also felt that my role as a doctor made participants feel comfortable sharing intimate information that they may not have volunteered to others.

### **7.1.3 *Seeking fertility investigation: Consulting the GP***

As is evident from this study, going through infertility investigation and treatment can be a long journey for azoospermic men. All the men interviewed wanted to understand more about azoospermia, find out why they did not produce sperm and what the treatment options and chances of success were. All but one man interviewed in this study decided to seek medical attention following failure to conceive after trying with their partners for a period of time without success. One man was not trying to have a family of his own at the time and decided to seek further investigation following the advice of his brother who was diagnosed with a potentially genetically transmissible form of male infertility. Some men said that pre-existing circumstances, such as the inability to conceive with a previous partner, or conditions

such as undescended testicles, raised some concern that there might be a fertility issue on their side. Despite this, these men were reluctant to seek medical advice early, because of fear that their worry would come true. These men might not have experienced the personal 'shock' that others might have experienced, but they did say that they felt devastated when they found out about the diagnosis.

As discussed in Chapter 2, the research literature to date indicates that men in general are less likely to employ medical services, as compared to women (Gijsbers van Wijk et al., 1992, Jackson, 1991, Griffiths, 1992, Neighbors and Howard, 1987, Rafuse, 1993, Gannon et al., 2004). With regards to infertility, women are the first to recognise delay in conception as a problem and to initiate investigation (Lalos et al., 1985, Greil et al., 1988, Morse and Dennerstein, 1985, Berg et al., 1991). This role of female partners in seeking infertility investigation and treatment was central in the findings of this study. None of the men appeared proactive to seek medical help, even in cases where the men had suspicion that the problem could lie with them, and the majority of men said that it was their female partners that initiated infertility investigations through their GP. It was therefore confirmed once again that women are more accustomed to seeking routine reproductive health care than men. This could be because women are used to interacting with medical services more frequently than men, for reasons such as routine cervical screening and family planning. They are therefore used to seeking medical advice often. The reluctance of men to seek help could be attributed to the fact that infertility problems are often seen by men as a 'woman's responsibility'. In addition, the lack of awareness about male factor infertility, which was once again highlighted in this study (see 4.3.1.2), makes men think that it is the woman's responsibility to ask for help.

All men that were interviewed in this study said that both they and their partners attended the initial appointment with their GP for the fertility investigations, but women always initiated the referral. Consulting the GP was seen as the 'woman's job'. This is in keeping with current literature findings that report men to be less likely to engage with the fertility services, at least at the beginning (Miall, 1985, Stanway, 1980, Owens, 1982, Meerabeau, 1991).

Some authors in the past have highlighted that part of the reason why some men do not engage with the infertility services could be the organisational aspect of such services, and because the majority of fertility clinics are usually part of gynaecology departments (Meerabeau, 1991). They pointed out that lack of engagement could be

due to attendant embarrassment and failure of the clinics to identify with their male patients. This appears to be also reported in more recent studies who conclude that men reported feelings 'sidelined' during couple's infertility investigation and treatment process (Hinton and Miller, 2013). Unlike other clinic settings, where fertility services may still be predominantly part of gynaecology clinics, participants of this study attended the Newcastle Fertility Centre, where couples are consulted in a dedicated Andrology clinic, and where clinicians use a separate male clinical file as a means of recording consultations and investigation results. A clinical relationship is developed between both men and women, and the partners are invited and are consulted as a couple. All men that were interviewed in this study said that they found this arrangement supportive.

#### **7.1.4 Are GPs unsympathetic to infertile men?**

GPs appear to have a central role in diagnosing male infertility, as they are the first point of contact for sub-fertile couples, initiate investigations, are responsible for making timely referrals, and potentially could offer ongoing support to couples that go through treatment. To my knowledge, this study is the first to explore the experience of men receiving the diagnosis of azoospermia at the primary care level. While men described 'good' as well as 'bad' experiences of medical care in general practice, it was the lack of knowledge about male infertility as well as the lack of emotional support by GPs that was highlighted by many. Men who described negative experiences with their GPs mentioned that they found out about the diagnosis in an abrupt, and in some cases, in an insensitive way and lacking in empathy. Some men expressed the opinion that their GPs did not take them seriously and did not seem to understand the impact of the diagnosis of azoospermia on their lives. They felt that their GPs could have had more understanding about the implications of the diagnosis for them.

Another important element that emerged from the interviews concerned the GPs' explanation of the men's health problem. Some men perceived their GPs as dismissive because they lacked detailed knowledge on male infertility, and appeared to want to rush their consultation and refer them on to a fertility specialist. They felt that their doctor did not give them enough information or an adequate explanation about the possible reasons for their diagnosis, and what the possible treatment options were. Men were often left wondering if there was any effective treatment available for their condition. This lack of knowledge by some GPs could be due to the

fact that they don't see couples with infertility, and in particular men, very often. The perception of lack of empathy described above could be because the men felt that the GPs lacked knowledge about their condition, and therefore did not appreciate this fact, and saw their doctor coming across as unsympathetic. In response to this finding, and in order to make them aware, it is worth considering better informing and educating local GP groups about male infertility.

One man highlighted that he would have liked to have access to professional counselling whilst waiting for his specialist referral appointment. Although clear guidelines exist on which tests GPs should carry out for infertile individuals, there is little guidance on the role of primary care in information giving and emotional support for men and couples awaiting tertiary infertility referral (NICE, 2013). This was therefore a new and interesting finding of this study, because a lot of emphasis is given on the availability and provision of counselling services for patients already undergoing ART (NICE, 2013), but this comment highlighted the importance of counselling being accessible from the time of the initial diagnosis in primary care. Considering the length of time that the initial GP referral to a tertiary centre can sometimes take, the above interviewee's comment highlights the need for detailed information provision, e.g. in the form of an information leaflet or fertility support group, and access to counselling at this early stage. The uncertainty surrounding the diagnosis of azoospermia, and the implication with regards to further investigation and treatment, can often make patients feel 'lost' at this early stage, and not knowing who or where to turn to for support. They might therefore find it helpful to contact a fertility support group or speak to a counsellor if they wish.

### ***7.1.5 Male infertility awareness and reaction to the diagnosis***

Male infertility appears to be as prevalent as female infertility (Karavolos et al., 2013). Yet, this study highlighted the lack of awareness about male infertility amongst men. The majority of men interviewed in this study appeared to be unaware that male infertility, and in particular azoospermia, could occur in men. Several men said that they always assumed infertility to be 'a woman's fault' and never expected that such problem could occur in men. As such they took their fertility for granted. One man recalled becoming concerned about his fertility after his girlfriend pointed out that infertility can occur in both men and women. Another man said that because of the rest of his family were able to produce children, he did not believe that the problem could lie with him. This fact, that men did not perceive themselves as having a

problem, could explain their apparent reluctance to seek help and the 'shock' experience by these men when they find out. Three men however did report that they saw the problem as a potentially attributable to either of the partners or as a joint problem.

As discussed in Chapter 2, the key factor that determines the impact of infertility on individuals and couples is the strong desire to have biological children. This desire depends on many factors, including the experience of being raised in a family, the individual's motivation to become a parent, personal and shared values, as well as cultural and social norms. The majority of participants in this study reported that they were shocked by the news of their diagnosis. Denial, devastation, confusion, frustration, sadness and disbelief were amongst the most frequently experienced emotions that were described by men that participated in this study. Some men attributed those feelings partly to the fact that they had always assumed infertility to be a female problem. This expression of negative emotions by infertile men upon discovery of their infertility diagnosis is consistent with those reported by other authors (Menning, 1980, Van Hall, 1983, Watkins and Baldo, 2004).

For many men the diagnosis brought feelings of shame and guilt for letting their partners down and for not being able to give them what they wanted. One of the participants said that the diagnosis made him feel as if it was the end of the world. It shattered his dream to have children and be a biological father, which for him was 'the ultimate life goal'. Some men on the other hand, had been wondering 'what was going on', because of the inability to get previous partners pregnant, or because of conditions such as undescended testicles, which they knew might affect their fertility. These men did not experience a deep sense of shock, but did feel sad upon learning of the diagnosis, and some reported a feeling of relief and sense of closure for finding out the truth about their condition.

Men diagnosed with infertility appeared to have gone through a process of grief and loss, similar to that described by Menning (1977), an unexpected 'life-crisis' event, where the initial denial serves as a temporary defence for what has happened and allows time for adaptation and development of coping mechanisms (Menning, 1977). It appears that for men, this denial provides an initial deviation from the painful reality of infertility. The lack of knowledge about male infertility might have contributed partly to the sense of shock and disbelief that these men expressed. Most men felt unprepared about the diagnosis, especially in the absence of any biological

indicators of illness. For those men therefore, the diagnosis of their own infertility shattered their previously 'taken-for-granted' perception of being healthy and able to reproduce. One participant of African heritage and Christian faith, said that both he and his wife felt guilt and self-blame for disappointing their families upon discovering his diagnosis. He explained that he knew some people who were childfree either by choice or due to a medical condition, but talked about how important children were to him and his family and explained how important was having a large family with lots of children. Cultural beliefs therefore can affect men in different ways.

Frustration and anger seems to originate from the inability of men 'to be in control' of their body. Anger occurs when denial cannot be maintained any longer and the realisation of the 'reality' (Menning, 1980). Most men in this study said that they were frustrated as well as angry, because they had 'lost control' over their body. Some men described this as 'unfair', and the lack of answers of a specific cause for their infertility, made them feel more frustrated.

Men in this study also expressed a deep sense of sadness upon discovering their diagnosis. They said that this was due to their inability to fulfil the role of making their partner pregnant, and continue their family line. This reflects the results of other studies, in which men experienced significant grief because of failure to carry on the family line (Lee and Sun, 2000). Infertility, unlike other significant events that are time-limited, can continue for many years, causing individuals to go through what has been described as 'a roller-coaster' of emotions (Blenner, 1990b, Diamond, 1999).

There is a wealth of research indicating that many individuals describe a sense of self-blame and failure upon the discovery of their diagnosis (Abbey et al., 1995, Daniluk, 1997, Inhorn, 2003) . They see infertility as personal failure because most view the ability to reproduce as a key aspect of their personal identity (Matthews and Matthews, 1986). Consistent with available literature, men in this study expressed feelings of personal failure and self-blame for not being able to meet their partner's expectations. The sense of failure in these men was augmented by the perception that the failure of their bodies to produce sperm also denied their partners a child. For some men this was difficult to come to terms with, because, as one man put it, children was an 'important feature' of their relationship and he said that he felt like 'letting his partners go' because he felt guilty that he could not provide her with what she wanted. Two men said that they felt depleted of confidence and not sure of their

worth to their partners. These men felt anxious and afraid that their partners would leave them, if they could not have children.

#### **7.1.6 Visiting the specialist clinic**

Most men mentioned that they had to wait a long time for their appointment at the specialist clinic. Information provision was important to participants. Men expressed their concern that they did not receive enough information on what to expect at the specialist clinic. This was because of a combination of factors; the patients were not well advised by their GPs of what would happen in the fertility clinic and the information sent by the clinic to the patient was not clear in explaining what patients should expect. Some men felt nervous, and described their initial experience as 'daunting'. This was mainly because they did not know what to expect, and they were asked to talk about their private lives. For some men this attendance at the clinic was their first ever visit to a hospital. One female partner also explained that she did not herself expect to be examined at the same visit. This is something that often happens in tertiary fertility centres; both partners are assessed, irrespective of the reason for the original referral. This finding highlights the importance of providing clear information, including what is expected from each participant at this initial visit, and that both partners are likely to be examined, in order to reduce the stress of couples prior to attending the fertility clinic.

The long waiting time between the initial semen analysis and this lack of information, left men (and couples) feeling 'lost' and not knowing where to turn to, whilst waiting for their specialist clinic referral. Some men said that they didn't even know that there were available treatments, and finding this out after their visit gave them a lot of hope, but they wished they could have found out sooner. Some couples also said that their visit at the specialist centre made them feel less isolated, as they discovered that others were going through similar problems. Once they had their consultation, the majority of men said that they were happy with the explanation given and that they felt confident and reassured about the service they received at the fertility centre. This opinion however could have been biased, as discussed further in Chapter 3, knowing that the interviewer was a healthcare professional working in the same centre.

The majority of participants described their experience of producing a sperm sample for analysis 'unnatural', 'unpleasant' and 'embarrassing'. Producing a semen sample

for analysis 'on demand' could stir up complicated emotions of inferiority, humiliation and shame in some men (Meerabeau, 1991). In addition, it puts men under a lot of pressure to 'perform'.

The experiences of men with regards to the semen sample production and facilities were variable. Some men said that the facilities were 'fine', but the interviewer felt that these men were uncomfortable talking about their experience in this area, and tried to bypass the subject. Others said that they found the sperm sample production facilities far from ideal, and suggested that more sound-proofing and privacy was required. One man said that he felt the magazines available in the room made him feel 'strange', because they made him feel as if the purpose for doing the sample was other than for medical reasons. Indeed some authors argue that even in fertility clinics, the semen analysis, which is the routine male fertility test, could be seen as not a purely 'medical' act, but as having strong sexual connotations since it involves masturbation and is aided by mild pornography (Meerabeau, 1991). There is evidence however that the use of erotic material in the fertility setting can aid semen sample production and is required by some men (Crawshaw et al., 2007). As these authors suggest, consideration should therefore be made by fertility clinics to highlight that the use of erotic material, although available, is optional and a choice for the individual.

It is important to highlight that these views reflect the facilities in one fertility clinic only, and come from a group of participants with a broadly similar cultural background (majority white British men). It does however reflect the importance that men give to such facilities in the fertility clinic. Semen sample production facilities are an area that is relatively unexplored in the current literature, possibly because it is a sensitive subject. Although the results of this study cannot be generalised, the findings highlight the importance of privacy and sensitivity needed when approaching the subject of semen sample production.

Men reported that the attitude of the specialist fertility clinic staff was exceptional, and this came across as one of the strongest points of the infertility care provided to men with azoospermia at Newcastle Fertility Centre. The fact that the interviewer was a clinic member staff, however, could have served as a confounding factor for the interpretation of this finding.

### **7.1.7 *The search for a cause***

As emerged from this study, following the diagnosis of azoospermia men feel powerless and 'out of control'. They will always want answers as to what the actual cause of their condition is. The majority of men interviewed questioned their past behaviours and lifestyle choices and spent time thinking about what could have been the cause of their azoospermia, and tried to link it to past lifestyle choices.

They wondered whether lifestyle factors such as smoking, occupational exposure to certain chemicals or radiation, could have contributed to their problem. One man appeared to firmly believe that the cause of his infertility was exposure to environmental chemicals from a factory near a playground in the neighbourhood where he grew up.

It appears that it is the lack of control over their condition that men found most difficult and distressing. The lack of knowledge and uncertainty about whether there are any effective available treatments was also another worrying issue for men. Unfortunately, a specific cause is not identified in up to 50% of cases (Karavolos et al., 2013). As evident from past research, unexplained or 'idiopathic' infertility can be particularly stressful (McEwan et al., 1987, Daniluk, 1988, Daniluk et al., 1987) The inability to offer an explanation can also be difficult for healthcare professionals who often have to admit that they don't know the reason for the man's problem. This study therefore highlights once again that further research is needed in the area of male infertility causes.

### **7.1.8 *Preferred sources of information and support***

#### **7.1.8.1 *The Internet***

The Internet is very widely used for medical information gathering. Studies highlight increasing internet use among people with infertility problems (Hinton et al., 2010). Internet forums could help men realise they are not alone in facing infertility issues, can inspire hope, and help men develop new friendships. On the other hand, the use of the internet can be associated with problems. It can leave patients isolated from real world interactions and communication, as well as expose individuals to other people's experiences which could lead to feelings of sadness or psychological distress, lead to upsetting misunderstandings and make them become pre-occupied with their condition (Malik and Coulson, 2008). The Internet offers a new outlet that is

available 24 hours a day, seven days a week, whenever people feel they need it. In addition, one revolutionary element of Internet communication is anonymity.

Men that took part in this study did not seem to find the same levels of support online as their partners. It appeared that men's partners were more proactive in looking up information from various sources, such as the internet, leaflets and TV programmes. The few men who looked online commented that they found it hard to find information about male infertility.

#### **7.1.8.2      *The clinic***

Clinic-provided information and discussion with clinic staff were the most strongly preferred sources of information for men attending the clinic. Only two men confided in friends for information and support, who were also experiencing fertility problems. Therefore, the findings of this study support other authors' reports (e.g. Hammarberg et al. (2010)), which found that men rely predominantly on clinic-provided information and support, and do not use wider sources of social support, such as online forums or discussion with friends. The reason for this could be the fact that there is still a lot of stigma surrounding male infertility and men are reluctant to talk openly about this, fearing that they will be marginalised and ashamed. This knowledge highlights the fundamental importance of information provision and psychological support through the clinical care provided to men diagnosed as infertile, and this should be recognised as an indicator for providing comprehensive, high quality healthcare for men diagnosed with male factor infertility. This study also highlighted the importance of the female partner's support throughout men's experience of infertility.

#### **7.1.8.3      *Professional counselling***

A number of authors report that men appear to be less receptive to psychological counselling than women (Daniluk, 1988, Wischmann et al., 2001, Wischmann, 2008, Wischmann et al., 2009). This is because men do not usually adopt a coping strategy based on social support (Abbey et al., 1992; Stanton et al., 1992) and are more reluctant to ask for help. Guilt, frustration, marital problems and lack of confidence have been described as potential reasons for men attending professional counselling sessions (Edelmann and Connolly, 2000). The majority of participants did not indicate openness towards psychological counselling. Only two men in this study mention that they considered taking up psychological support, and the majority confined themselves to their partner's support, which they reported to be adequate.

There is evidence that men (and couples) want reassurance that psychosocial services would be available if needed, even though such services may never be used (Boivin et al., 1999). An alternative option to counselling could be the provision of detailed written information at the time of diagnosis about common emotional and psychosocial reactions to infertility in men, on coping strategies with their condition and other relevant issues. Validated questionnaires concerning men's views of their infertility could be used as a 'predictor' for taking up infertility counselling (Boivin et al., 1999).

### **7.1.9 Effect on masculinity**

Masculinity is generally defined by strength and independence. Existing literature supports the fact that male fertility, sexuality and masculinity are deeply intertwined, with the majority of men experiencing a sense of loss of masculinity upon discovering the diagnosis of infertility (Berg and Wilson, 1991, Elliott, 1998). The male body is portrayed as vigorous and robust, a projection often indicated through physical and sexual prowess (Potts, 2000). Cudmore (2005) argued that for some men infertility can denote a lack of virility and masculinity, which is often felt to be more troubling than the actual denial of the opportunity to become a biological parent. It appears that for men infertility is often seen as a potential marker for experiencing sexual problems. In this way infertility challenges central aspects of identity and self, and points to the fact that masculinity is based on more than symbols such as physical appearance (Clarke et al., 2006). Contrary to existing literature, however, only a minority of men in this study perceived the diagnosis of azoospermia as a loss of their sexuality and ability to live up to traditional masculine standards. The majority of men in this study did not appear to associate infertility with their masculinity, and they felt the diagnosis of infertility did not make them feel 'less of a man'. Although studies suggest that sexual behaviour and successful reproduction is the ultimate expression of masculinity and personhood for men (Elliott, 1998, Potts, 2000), in this study it appeared that failure in one domain (fertility) may not necessarily reflect inadequacy in the other (sexual performance).

Contrary to existing literature findings regarding to the effects of infertility on masculinity, thirteen participants interviewed in this study did not report the feeling of loss of masculinity upon discovering the diagnosis. They felt that there was no reason to 'feel less of a man' because it was not their fault and it was not because of something they had done. Men said that they did not want to be embarrassed about

it, because there was no reason to be, and if they had any other clinical condition, people would not condemn them, or look at them in a different way, so why should they feel any different about this? Two of the participants however perceived their infertility to be a sign of personal weakness and inadequacy, with some expressing a feeling of loss of masculinity.

#### **7.1.10 Stigma**

The findings of this study indicate that the issue of male infertility continues to be a taboo, and stigma remains a strong problem in male infertility. With the advancement of reproductive technologies, male infertility and its treatment is rapidly emerging as a medical condition and is gradually gaining more acceptance, especially in Western societies (Wischmann and Thorn, 2013). The existence of the psychosocial aspects of male infertility have more recently been recognised (Wischmann and Thorn, 2013). There still exists a potential stigma about male infertility, to a greater degree than female infertility, and this could be because male sexuality and masculinity has been linked to performance in a way that female sexuality is not (Meerabeau, 1991).

Men with fertility problems are generally more subject to ridicule, as compared to women, and some authors have reported that fertility problems can be psychologically traumatic and unconsciously be equated with impotence (Snowden, 1984). The findings of this study are in agreement with the current literature that talking about male infertility remains a taboo. This could reflect the effect of anticipated reactions on information sharing and the extent of the stigma that these men associate with their condition (their own perception of stigma), rather than how they themselves feel about it.

With regards to stigma, the findings of this study are in keeping with other research that shows male infertility to carry a significant degree of stigma, with men fearing that disclosure of their problem could lead others to think less of them (Greil, 1991, Miall, 1985, Miall, 1986). Male infertility did not appear to affect how men felt about themselves, but they were concerned how others will perceive them. As discussed earlier, men with infertility often feel a degree of shame, guilt, anger, and a sense of personal failure (Daniluk, 1997). Research also suggests that infertility is more socially acceptable for women than it is for men (Rowland, 1985) and that women would receive social support to help them cope with the diagnosis of female infertility, whereas men would be socially ridiculed (Carmeli and Birenbaum-Carmeli, 1994). It has been suggested that the stigma associated with female infertility could be seen

as less damaging compared to the stigma associated with voluntary childlessness. This is because some women who choose to be voluntarily childless can be perceived as selfish, career-driven, or abnormal (Chancey and Dumais, 2009) and therefore women who desire to mother, but cannot, would prefer the label of “infertile” rather than be perceived as lacking a desire to be a mother (Steuber and Solomon, 2011). Openness about infertility by women therefore has been described as a positive factor in coping with involuntary childless (van Balen and Trimbos-Kemper, 1994), because in this way women appear to clarify their position to their social network. It appears that the perception of stigma that is associated with male infertility leads to a higher degree of privacy. Another reason that men find it difficult to share the diagnosis even with their family, could be the fact that infertility is related to sexual intimacy, and this can inhibit general discussion, in turn leading to a sense of isolation and loneliness (Gerrity, 2001b). It has also been suggested that male infertility may be associated with a higher degree of secrecy, because of fear for the future disclosure of the genetic origin of possible offspring, after donor insemination treatment (Brewaeys et al., 1993).

#### **7.1.11 Effect on relationships**

The results of this study align with evidence that infertility does not have a negative impact on a couple’s relationship. While infertility can lead to stress and communication difficulties between partners, couples generally report that infertility has brought them closer together (Greil, 1997). Several authors have reported that infertility does not lead to relationship or sexual problems amongst partners (Pasch et al., 2002, Daniluk, 2001, Hjelmstedt et al., 1999, Schmidt et al., 2005). Infertility can be seen as a shared experience between partners, which in turn strengthens their relationship (Webb and Daniluk 1999). Some authors however found that infertility can have a negative impact on relationships and lead to breakdown (Wirtberg et al., 2007, Sundby, 1997).

The majority of men in this study said that they were able to talk openly and share their feelings about their problem with their partner. These couples said that they shared their disappointments and frustrations, but also pointed out that at times there was tension and conflict in their relationship. All but one man in this study said that they did not feel the need to have any private discussions with a counsellor, or healthcare professional without their partner being present, a fact which once again highlights that most individuals go through this problem as a couple, and that the

actual problem brings them closer together. One can argue however that couples did not want to disclose their conflicts to the interviewer, for fear that the interviewer would be judgemental towards their feelings. No difference was evident in what was said by men that were interviewed on their own, or with their partner present.

Two out of fifteen couples reported communication difficulties and said that the diagnosis of male infertility felt divisive for them. They described talking very little about their infertility, especially at the beginning, as they found it a sensitive and painful subject to talk about. Men described that these failures in communication made them feel unsure of whether they were supportive enough to their partners and increased their guilt for being unable to satisfy the desire of their partner to conceive. One man described how he became defensive and could not talk about the problem with his wife, because he did not want to talk about an issue that was 'his fault'. Some couples therefore kept things to themselves (see 7.1.11), a fact that made individuals feel more isolated. Cudmore (2005) found that the lack of social support around infertile couples could intensify the pressure on them to provide support for each other. Keeping their infertility a secret makes their problem 'invisible'. This finding highlights once again the importance of access to counselling for men and couples, in order to help them encourage each other to talk about their problem and express their feelings openly, rather than 'suffer quietly'. It is important for healthcare professionals to be aware that male factor infertility can lead to relationship difficulties, even though some couples may not want to openly admit this, and therefore offer couples' counselling in everyday clinical practice. For couples that don't talk to each other openly, it would encourage conversation and reflection on their experiences, and contribute to the quality of their relationship.

The present study explored the effects of male infertility on relationships at a 'baseline' period, at, and immediately after, the diagnosis of azoospermia. It will be interesting to examine what the impact of longer periods, for example 2-5 years, of unsuccessful or successful male infertility treatments are on men's marital relationship and emotional wellbeing.

#### **7.1.12 The disclosure experience and seeking support**

One of the most difficult and personal decisions men had to make was whether or not to disclose the diagnosis to close family members, friends and work colleagues. Some men chose to keep their diagnosis a secret, others were selective of who they told, and some were more open. All men and their partners that participated in this

study were comfortable talking to the researcher about their infertility experiences. All participants said that they disclosed the diagnosis to their partners, but the majority of couples kept the information within their relationship or very close family members. One couple decided to keep their diagnosis and treatment a secret from the beginning, and did not inform close family members or significant others. The details of male factor infertility, the treatment process, and the subsequent treatment outcomes involve a lot of private information about individuals and couples, and this is therefore one of the reasons that men in this study did not want to disclose the information to others. Due to the sensitive nature of male infertility, men chose not to divulge the details of their experience to anyone other than those individuals closest to them. This finding is in agreement with past research available on this point that suggests couples experiencing difficulty conceiving often report a high degree of secrecy from people around them (Miall, 1986, van Balen et al., 1996). This secrecy stems not only from the fact that it is difficult to talk openly about one's infertility (Exley and Letherby, 2001), but also from the fear of being negatively stereotyped or stigmatized (Greil, 1991). Some authors also claim that within this context, often there is a source of tension between wanting to maintain privacy and wanting to reveal personal information to people, in order to gather comfort and support (Steuber and Solomon, 2011).

But why do men (and couples) sometimes chose to keep their infertility diagnosis a secret? Evidence suggests that aspects of stigma, communication efficacy, and closeness to social networks have a significant impact on infertility-related disclosures (Steuber and Solomon, 2011). The reasons men gave for not wanting to disclose the diagnosis varied. Most men said that they wanted to keep it to themselves because it was a private matter. In general, reproduction is a private topic, and these men felt that the details of their infertility were too sensitive to disclose outside their marriage. Others did not want to tell their family, in fear that they will make them feel guilty that they are responsible for their infertility. Men explained that the difficulty in discussing their infertility with others was because they feared that they will be negatively stereotyped or stigmatised and people around them will see them differently. They came across as feeling ashamed of talking to others about it. They felt the need for secrecy in order to protect themselves from embarrassment, shame and disappointment. Indeed, two participants said that their work colleagues made jokes about them or their relatives kept asking them, which

made them feel uncomfortable. The perception of stigma amongst these men was therefore significant (see section 5.1.4), and these results suggest that the men wanted to protect the information and keep the diagnosis secret to avoid being stigmatised.

Two men said that they did not see the point of discussing their problem with other friends because they felt that their friends would not understand what they were talking about. They didn't want other people to know, in case treatment did not work and then they had to explain this to others who kept asking. They felt it wouldn't be easier to go through treatment secretly, because if it didn't work then they could keep their grief private.

Some men said that the benefits gained from sharing their infertility diagnosis with friends and family can sometimes be offset by the potential for negative consequences. Disclosing the diagnosis and being open about their infertility could affect their relationship with other people. For example, opening up might mean that some friends might want to distance themselves, fearing that if they invited them to parties with children they could make them feel worse, and this could lead to further isolation.

It is generally believed that women have larger social networks than men, and find protection from emotional loneliness through those social network relationships (Dindia and Allen, 1992, Antonucci and Akiyama, 1987). By interviewing a small number of female partners in this study, identified that the highest degree of disclosure occurred between female partners and their mothers or female friends. It appears that men rely more on their female partners rather than social networks, for emotional and social support (Dykstra and Jong-Gierveld, 2004, Steuber and Solomon, 2011). The findings of this study replicate this point to some extent, by showing that for men, the tendency to share their diagnosis externally was inhibited, most likely due to the fact that the men are feeling stigmatised. It appears that men handle their feelings of stigma better within their relationship, whereas women prefer to outsource some of their emotional support needs. This could also explain the low uptake of counselling by infertile men as compared to women. Future research could address the question how female partners handle information in case of male infertility, and whether there are differences between disclosure patterns for couples who are coping with male-factor infertility as compared with those who suffer from

female or an unknown causes of infertility. It will also be interesting to see if stigma itself is contributing to couples offering vague or inaccurate answers for the cause of their infertility.

Most participants said that 'being a man was the most difficult thing' because you don't have anyone to talk to. If you talk to people they will make a joke of it. The only group of men that these participants could talk to were men with similar problems, because these men had an understanding of what they were going through. Men therefore felt that concealing the information was a way of self-protection, in order to avoid embarrassment, judgement and ridicule. This highlights the importance of developing online forums and resources, or focus groups, so that men can get information and support from each other, in a more 'confidential' way.

Three men mentioned that they did not want to disclose their diagnosis to their bosses or work colleagues, because they felt that if they knew that they were thinking about having a family this could have affected their work prospects. The reason for this could be that men (and their partners) might have been worried that their employers would think they were less committed to their jobs, because of the problems they were going through. Some men (and their partners) also said that this contributed to the fact that they often gave vague or inaccurate reports, when it came to requesting leave from their employer to attend medical appointments. This observation is not limited to azoospermic men, as other authors report that men who banked their sperm for fertility preservation were reluctant to take time off work, in order to monitor their natural fertility, fearing that disclosing the diagnosis to their employers and work colleagues would trigger jokes and suggestions of compromised masculinity (Eiser et al., 2011).

Also they did not want people constantly asking them about it or the progress of their treatment. Some men chose to speak to very few close friends, but they did not reveal the details of the actual diagnosis, because they didn't want them asking them too many questions. This highlights what factors influence the extent to which infertile men and their partners engage their social network when coping with their infertility diagnosis.

#### **7.1.13 *Deciding to have an operation and the use of donor sperm***

The experience of infertility treatment is unique, in that individuals do not always know what caused their infertility and what the outcome of their treatment would be.

They do not know whether they will be permanently infertile or whether they will eventually become biological parents. They therefore go through what has been described as a 'rollercoaster' of positive and negative emotions.

Some men underwent more invasive treatment, in the form of an operation to have sperm extraction directly from their testicles, under general anaesthesia. Through the interviews with these men, one of the aims of this study was to assess the personal, medical and psychological factors that influence their decision to undergo, or not, a sperm retrieval operation. Close analysis of their response showed that the decision-making process with regards to surgical sperm retrieval was fairly complex and involved their partners to a great extent.

The results of this study showed that most men that decided to have the operation did so because they saw it as their last hope to do everything they could to have their own biological child. Even if the operation turned out to be unsuccessful, they felt that it was a way of achieving closure and 'moving on'. It was interesting to find that some men saw going through the operation of little benefit, when considering the low overall chances of success in retrieving sperm and the potential complications associated with such operations. Importantly, the partners of some of these men had an important influence on the decision to have the operation. Some men said that their partners had pushed them to have the operation, before considering sperm donor treatment, despite them saying that they would probably have gone for donor sperm treatment or adoption in the first place. These men explained that the decision of their partners was based on the fact that they would have liked to have the biological children of the men they chose to be with (i.e. them), before considering any of the other two options.

Factors that influenced men's decision to undergo a sperm retrieval operation, or not, included the potential short and long term complications associated with this operation. The female partner's appeared to have a big say in this decision also, and in some cases appeared to pressurise their partners to undergo an operation, who accepted that in order not to upset the dynamics of the relationship. No specific literature is currently available looking on the male patient's perspective on the decision making process to undergo a sperm retrieval operation or to use donor sperm for treatment.

## **7.2 Learning from men's experiences and recommendations for clinical practice and future research**

The findings of this study indicate that the diagnosis of azoospermia in men can have a significant impact on their everyday lives. It is hoped that these findings will help health care professionals and counsellors who work with infertile men to provide a more effective clinical service. The following paragraphs discuss a number of 'lessons' that can be learned from this study's participant experience.

1. Information provision appeared to be of paramount importance to interview participants. The majority of men reported a lack of information provision by their GPs and stressed the importance of improving GP knowledge on male infertility. In addition to GPs performing the initial investigations and swift referrals, participants wanted to receive appropriate information and support from their doctors, in order to help them deal with their condition. Evidence from available research suggests that couples have a better experience of infertility management when communication with each other and with the GP is strong, and when the GP had a 'special interest' in fertility issues (Wilkes et al., 2009). It is important that healthcare professionals make sure that the patients have understood the received information and further research should be done on the ability of healthcare professionals, including GPs, to convey the diagnosis of infertility correctly and in a sensitive manner to their patients. It will be interesting to see if there is a difference in this respect between male and female infertility, as diagnosed and explained by the GP. It is important for GPs, and fertility specialists and nurses to take the time to assess the meaning of infertility to these men and provide appropriate information and support at the early stages of the diagnosis, in order help them compensate against infertility-related stress. Acknowledging the challenges and giving appropriate information about what they may face during the treatment process will help men and couples deal with their infertility in a better way, and become more open about their infertility. For males attending fertility services for the first time, information about the nature of the possible necessary investigations and clinical examinations will be useful. There is evidence that a significant proportion of infertile couples use the Internet to get information about their infertility (Hinton et al., 2010), and this, in addition to providing written

information in the form of leaflets could be an acceptable way of providing such information to men before their clinic attendance.

2. Men appear shocked and surprised about their diagnosis, and this was because many of them were unaware that male infertility exists. Some said that they found the investigation process daunting because they receive little information about what to expect during their visit. The initial experience of the diagnosis, as conveyed by the GP, appears to be highly important and has a significant role to play on how further experiences of men undergoing investigation and treatments are shaped.

For men, the psychological impact may be larger, because often no cause of their infertility is identified. Many men may experience shame and guilt for not being able to fulfil the role of giving children to their partners and continuing their family line. It is important to be aware of the contextual factors that influence the impact of infertility on men's lives. For example, the impact of infertility can be dependent on how supportive the man's partner is. It is also important to recognise that for some patients, the inability to have children and the discontinuation of a family line can be much more traumatic in some cultures than others. One participant in this study, who was of African background, explained how difficult this was for him and his wife not to be able to have children. It is therefore important for healthcare professionals to take into account cultural values when making their recommendations to men and couples who experience infertility, and to appreciate that the grief experience could be more traumatic in some cultures than others.

The finding of this study confirms that the men with azoospermia and infertility often feel isolated. Healthcare professionals should be aware that due to the lack of awareness and the stigma surrounding male infertility, men are often left in a state of shock and disbelief upon discovering the diagnosis of azoospermia. Many of them discover for the first time that infertility can be attributed to men.

Healthcare professionals should be aware of the intrusiveness and distress caused by the diagnosis of azoospermia and its treatment, in order to help patients make practical, informed choices about treatment and help them make their informed decisions.

3. Men still don't talk about their infertility and don't use the internet for information and emotional support. Instead, they tend to 'bottle up' more because they are embarrassed about the diagnosis. The internet offers anonymity and can be an important tool in providing access to other's experiences. They can have access to reliable information and talks to people that are in the same situation. It could be that men don't use the internet because most websites are aimed for women, and therefore an infertile men's online community has not 'taken off'. The further development and publicity of websites addressing male infertility is therefore of great importance.

It is evident from the findings of this study that there is a need to raise awareness of male infertility. This will help some men and couples reach the diagnosis as early as possible and improve the patient's experience of care, treatment and aftercare, whether fertility treatment has been successful or not. Websites such as Infertility Network UK ([infertilitynetworkuk.com](http://infertilitynetworkuk.com)) and Health Talk ([healthtalk.org](http://healthtalk.org)), that provide information about health issues, can help patients obtain reliable information about their condition, see and hear people's real life experiences and help them understand what it is really like to have a health condition such as male infertility. Such online resources can also help bring patients in contact with others that suffer from similar conditions. Male infertility awareness could also be raised through publicity in male-oriented media, and there in comparing the prevalence of gendered infertility in related articles in female-oriented versus male oriented media.

Male infertility can make some men withdraw and feel isolated from close family, friends and others. Organising local male infertility support groups may be helpful for men to talk through their experiences with other men. This will make them realise that they are not alone. Being able to have access to online information and support groups could also help these men find information while waiting for treatment and feel less isolated. Of course, support groups and professional counselling are not for everyone. Some men might find it a 'painful' reminder to keep talking about their problems again and again. Encouraging openness about male infertility could be a positive way in helping men cope with their diagnosis (van Balen and Trimbos-Kemper, 1994).

From personal experience in our clinic, we know that some forms of male infertility can be progressive, with sperm production declining over time. Although in the majority of cases male infertility is asymptomatic, some men may experience specific symptoms, such as testicular pain or penile discharge, that point towards causes of male infertility. Some men in this study tried to retrospectively link past lifestyle choices and vague testicular symptoms to their infertility, and said that they wished they knew earlier that these factors could be linked to male infertility so that they could seek medical help before they reached a stage where medical help was not as effective or indeed possible. Raising awareness of such symptoms therefore could aid the timely investigation of such men when they present for investigation.

There appears to be a general lack of awareness about male infertility amongst men, a fact that could explain their reluctance to engage with medical services for fertility problems. Social research on other male-specific disorders, such as erectile dysfunction and the 'andropause', suggest that men nowadays may be more accepting of medical treatments as compared to previous generations (Szymczak and Conrad, 2006, Potts, 2000, Potts et al., 2006, Loe, 2004). These studies conclude that men are more willing to 'see the doctor' in order to seek help and try medical treatments when aspects of their masculine appearance or bodily functions are 'threatened'. This could therefore mean that more public awareness of male infertility that portray men as intelligent, well informed and willing to engage with medicine for personal gain, could improve their help-seeking with regards to infertility, and help reduce the stigma surrounding such diagnosis. In this way, men could become more open to talk about this taboo subject, rather than been seen as 'victims' of medical interventions. Public education should also be targeted at reducing the stigma of male infertility and enhancing positive attitudes towards help-seeking.

4. Infertile and childless men can receive stigmatising messages from colleagues at work, friends and family members, and therefore may be hesitant to seek counselling and support from these people. However, the use of online support groups, or telephone consultations may increase their willingness to seek professional help, by maintaining anonymity. Online forums and websites are an effective way of providing information about male infertility, available treatment options and outcomes (Hinton et al., 2010). It could prove a very important source

of support, as well as a source of information, for men who want to know more about their condition and work through the infertility process in private. Information can also be added on the different kind of problems that infertile individuals face, and how they can get help for these specific problems.

Discussing their condition openly with people that have similar problems outside their relationship, could provide men with a way to release the pressure of only discussing it with their partner. Current research indicates that counselling and psychotherapy are effective in reducing negative emotions and infertility-related stress for couples undergoing infertility treatment (Wischmann, 2008, Jordan and Revenson, 1999). However the majority of men in this study did not appear to be willing to access counselling, and felt that the support of their partner was adequate. Infertility and its treatment can be fairly complex, in that only people who have had similar problems can understand what others are going through. Healthcare professionals, including GPs, who understand why people can feel so isolated during treatment, will be in a good position to direct their patients to websites and forums that provide reliable information and support. Men in this study stated that they were interested in learning more about their condition and how it affects others. Most men interviewed in this study were open to the idea of holding a debriefing session with other participants of this study, in order to talk about and share their experiences in a focus group. This however was not possible due to time limitations in conducting this study.

It is evident from the results of this study, that knowing somebody with a similar infertility problem appeared to be a positive predictor for disclosure of the diagnosis to others. Development of online support groups or forums for men with infertility could make a good platform for patients to share their experiences of azoospermia. Communicating more openly with men who have similar problems will make them feel less isolated. Being able to read other men's experiences could be helpful to these men as it could help them 'open up' and discuss it, and realise that other people have similar problems.

Men react differently to women when it comes to the diagnosis of infertility. Many men may feel uncomfortable and embarrassed in talking about private issues such as sex and fertility outside their relationship. Men highlighted the importance of having a supportive partner, which in the majority of cases brought partners closer together, and was the key in coping successfully with the initial stages following

the diagnosis of infertility. Men in addition wanted to appear 'strong and in control' and carry their emotions in silence as a way to save face and avoid bringing shame to their close family. Contrary to previous research that showed male infertility to have a negative effect on masculinity, this study found that male infertility does not necessarily have an effect on masculinity.

5. Some participants in this study suggested that the semen sample providing facilities do need improvement. However this only reflects the experiences of men attending the Newcastle Fertility Centre, and could not be generalised. Further research is needed in this area as it is relatively unexplored in the current literature. Information and best practice sharing amongst clinic might also help.
  
6. As mentioned by one of the participants, results- giving immediately following the sperm retrieval operation may not be ideal, because patients tend to forget, especially when they feel drowsy under the influence of a general anaesthetic. It is therefore important to consider alternative ways for discussing results in a timely fashion, ideally with their partner present. A telephone follow-up consultation with the couple could be a way to discuss the results and the implications, soon after the operation. However, organising such a service could have logistical implications, because the involved healthcare professional would potentially have to organise this telephone call out of normal working hours. This could also involve 'breaking bad news' over the phone, if the operation did not yield any sperm, which is not an ideal situation, especially if the patients don't have access to somebody to discuss their immediate concerns with. Also, on some occasions, sperm biopsy samples need to be incubated overnight, looked at and re-analysed the following day, before a final result of the operation outcome can be known.
  
7. More research is needed on the men's perspective in regard to the clinical care provided, and the decision-making process for undergoing a sperm retrieval operation and in the use of donor sperm. The information that emerged from this study will hopefully guide men to make the decision about undergoing a sperm-retrieval operation or not, and will hopefully help couples making such decisions in the future easier.

### **7.3 Critical reflection on the methodology of this study**

This study used qualitative methods to help understand how men experience infertility. It contributes new knowledge about azoospermic men's experience of their diagnosis and going through infertility treatment. One of the strengths of this study's sample was that all infertile men (and couples) that participated had been diagnosed relatively recently (within the past two years) and were undergoing active treatment for their infertility, allowing them to offer in-depth and up to date perspectives on their infertility experience. It is important however to remember that infertility and its treatment is a process with an uncertain trajectory, and the issue of timing with regards to the duration of infertility and the duration of treatment should always be taken into account.

One of the limitations of this study's approach was its cross-sectional nature, which makes it difficult to separate the effect of the infertility itself from the stress of going through invasive treatment. This sample represents only men in couples who have been coping with infertility for less than two years. The psychosocial consequences of infertility are time-dependent. One could argue that men in this study had 'heightened' distress levels that made them react and behave in a different way, because they were at a point of actively seeking treatment. These feelings could possibly diminish over time, or men could have put their experience into another perspective as time moved on, especially depending on whether the treatment for their infertility was successful or not in helping them become biological fathers. This is a point that could be explored in future studies that take into account the progressive nature of the infertility experience, beyond the initial stages of treatment, and examine how men experience azoospermia over an extended period of time.

Most men diagnosed with azoospermia in this study had presented as part of a couple who failed to conceive following a trial period. It will be interesting to see how single men react and experience azoospermia, when diagnosed incidentally due to another medical problem (e.g. Klinefelter syndrome), when they find out about the diagnosis at an earlier stage of their life, and how this affects their future relationships and everyday life experiences.

With regards to the representativeness of the studied sample, it is important to note that the sample of this study was mainly drawn from white azoospermic men seeking treatment in a fertility clinic. Non-treatment seekers, non-whites and men from ethnic minorities were under-represented in this study, and therefore those and others that

chose not to volunteer could have reported different experiences compared to those who pursued treatment. Although these points were considered, a more diversified sample of men could not be selected for this study, because of the nature of our region's population. The inclusion of patients from different centres could overcome this problem in the future.

Qualitative research is often criticized for its sample size. The number of interview participants in this study may seem small, but this is not necessarily a shortcoming. As discussed in the methodology chapter, the study achieved data saturation, and therefore it would have been unlikely that more interview participants would alter its findings. The only shortcoming with respect to the sample size might be that the majority of interview participants were at the post-TESE stage, with a negative sperm retrieval operation result. This negative treatment outcome could have affected the men's perspective.

This study only examined the experience of azoospermic men and therefore its results cannot be extrapolated to other forms of male infertility. The themes discussed in the analysis reflect the experiences of participants suffering from azoospermia, and these results cannot therefore be extrapolated to other causes of male infertility, for example milder forms, that don't require a sperm-retrieval operation for treatment. It is important to note therefore that the transferability of this study's data is not possible for the general male infertility population. It should also be noted that this study examined the experiences of couples suffering from primary infertility, but it has not looked at couples with secondary infertility. However, studies which have compared primary and secondary infertility have found this distinction to be unrelated to levels of psychological distress (Greil, 1997). These studies however appear dated; a fact that once again highlights the need for further research in this area.

#### **7.4 Conclusion and summary of key findings**

To conclude, this qualitative study on men's perspective on the diagnosis and treatment of azoospermia has highlighted important facts that have implications for daily clinical practice in primary and secondary care, and identified gaps for future research. This study contributes to the field of male infertility by providing important knowledge on men who have reproductive concerns and who face the potential of not being able to father a biological child. These insights can be used by healthcare professionals to identify and prioritise aspects of care for improvement.

Keeping the study's limitations in mind, the results suggest that receipt of a diagnosis of male infertility is a difficult and painful experience for many men. Male infertility treatment entails embarrassment and the surrounding stigma is negatively associated with disclosure. This in turn can impact on help-seeking and support provision for these men. It is important for healthcare professionals to be aware that they play a very important role in constructing the experience of infertility in azoospermic men. Besides having a need for timely information provision about their condition, infertile men need continuing support and understanding. Whereas there is no doubt about the importance of clinical outcomes, it is also important to remember that quality of male infertility care is more than just treatment success.

Finally, more studies are needed to examine the temporal impact of infertility diagnosis in men and address the questions highlighted in the discussion above. Although clinical emphasis is important, seeing male infertility within its larger social context will help men and infertile couples cope with their infertility better.

For men diagnosed with infertility, a well-functioning relationship with their partner and close family can be a source of reassurance and security, and indeed help them to overcome their distress and move forward. It is important that male infertility becomes more widely recognised and less stigmatising. If partners can be helped to support and communicate with each other, during this process, this will help towards creating a solid foundation for them to cope with their problem and move forward.

## APPENDIX A

### Patient information leaflet

The Newcastle Upon Tyne Hospitals   
NHS Trust

Newcastle Fertility Centre at 

Bioscience Centre  
International Centre for Life  
Times Square,  
Newcastle upon Tyne  
NE1 4EP

Telephone: 0191 2138213  
Fax: 0191 2138214  
[www.newcastle-hospitals.nhs.uk](http://www.newcastle-hospitals.nhs.uk)

## Psychosocial Experiences of Men with Infertility

### INFORMATION FOR POTENTIAL RESEARCH PARTICIPANTS

*We would like to invite you to take part in a research study that aims to investigate the experiences and feelings of men diagnosed with fertility problems. Before you decide to take part, it is important for you to understand why the research is being done, and what it will involve. Please take the time to read the information on this leaflet carefully and discuss it with others if you wish. Please ask us if there is anything that is not clear or if you would like more information.*

#### What is the aim of this research?

In situations where a couple has difficulty conceiving, there is often a problem with the male partner's sperm. The reason for the problem with the sperm is often unknown. The aim of this project is to explore the impact the diagnosis of infertility has on your day-to-day life.

The study will aim to explore how men who have been told that there is no sperm in their semen feel, and to investigate their experience of going through further tests and having treatment. We will do this by conducting face to face interviews and we hope to gather information that will ultimately help patients with similar problems.

#### Why have you been chosen?

You have been chosen because you have a problem with your fertility and no sperm has been seen in your semen. By agreeing to take part in this study you can potentially make an important contribution to our understanding of how men feel about their fertility problem.

#### Do I have to take part?

It is entirely up to you to decide whether or not to take part in the study. If you decide to take part, a research nurse will contact you to arrange an appointment for you to come back to the Fertility Centre where you can go through the study in person and ask any questions you may have. Then if you are still happy to proceed we will ask you to sign a consent form and you can indicate whether you would like to take part in the study. If you don't wish to take part, please inform Dr Karavolos the enclosed slip within 6 weeks.

### **Will taking part in the study be kept confidential?**

All information collected during the course of the study will be kept confidential. Only the research team will have access to the study records. All personal information, including your name and address, will be removed and unique study number will identify you in the study. This information will be potentially identifiable by the research team only, but all precautions will be taken by the staff to ensure that it is kept confidential.

### **Will not participating in research affect my treatment?**

No. You can be reassured that your treatment always comes first and deciding not to take part in this study will not affect the outcome of treatment or the standard of care you receive.

### **What happens if I take part?**

If you decide to take part in the interview study, you will be invited to attend a 1-hour interview where we will discuss your experience of going through investigation and treatment for infertility. The interview will be audio-taped with your permission and then transcribed onto paper. Both the audio and paper record of the interview will be anonymised, i.e. all personal information deleted, so that no one, apart from the research team, can identify that it was your interview. The tapes will then be erased.

### **How will the information be used?**

The information collected from the study will only be available to the researchers. All information will be treated as strictly confidential. Your personal details will be removed so that you cannot be identified from it. Eventually all the information will be written into a report and we intend to publish the results in a medical journal. If you wish to receive a summary of the report, please ask Dr Karavolos.

### **Who is funding the research?**

Newcastle Hospitals NHS Foundation Trust sponsors this research and funding for this study is from The Royal College of Surgeons of England. Additional funding is being applied for. This research has been approved by the Local Research Ethics committee.

### **What if I am not happy with anything involving this research?**

If you are not happy with anything having to do with this study, please discuss this with one of the researchers or members of staff. If you are not happy you can also express any concerns or make a complaint through the normal NHS complaints procedures.

### **Is anyone else involved?**

The research team will be seeing anonymised information, and as such you will not be identifiable from this information.

### **Who is leading the research?**

Mr Kevin McEleny, *Consultant Andrologist*, Newcastle Fertility Centre and Professor Erica Haines, *Professor of Sociology*, Newcastle University and Dr Stamatios Karavolos, *Clinical Research Fellow in Reproductive Medicine*.

Contact for further information

For further independent advice about this research you can contact Alison Murdoch, *Professor of Reproductive Medicine* at Newcastle Fertility Centre on 0191 2138213.

Is there anyone else who knows how I feel?

We know from experience how stressful your treatment can be and how this can affect your relationships, either as a couple or with others. We offer a professional counselling service. Please telephone us to arrange an appointment if you think it may help you. There are also several support groups that you may find helpful (see below).

**Infertility Network UK (INUK).** The largest network in the UK offering information and advice by phone and face-to-face. It has groups throughout the country and also produces a range of publications on infertility. Tel: 08701 188088 or visit [www.infertilitynetworkuk.com](http://www.infertilitynetworkuk.com)

**Donor Conception Network.** A national support group for people who have conceived through donation and those considering it. They can give you advice and support and also the chance to meet parents with donor-conceived children. Call 020 8245 4369 or visit [www.dcnetwork.org](http://www.dcnetwork.org)

**National Gamete Donation Trust.** A national government-funded charity set up to raise awareness of and seek ways to alleviate the national shortage of sperm, egg and embryo donors. It provides useful publications for donors and recipients including information on donation and the law. Helpline call 0845 228 9193 or visit [www.ngdt.co.uk](http://www.ngdt.co.uk)

Thank you for taking the time to read this information leaflet.

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**Research study: Psychosocial experiences of men with infertility**

Please indicate below whether you wish to take part in this study or not by deleting as appropriate.

I do / I don't wish to take part in the study.

Name: .....

Address: .....

Tel: .....

Email: .....

Please return completed form in the enclosed pre-paid envelope to: Dr Stamatios Karavolos, Newcastle Fertility Centre at Life, Times Square, Newcastle upon Tyne, NE1 4EP. Tel 01912138213

**Appendix B**  
**Consent Form**

**CONSENT FORM**

**Consent Form to Participate in a Research Study**

**Title of study:** Psychosocial experiences of men with infertility.

**Researcher:** Dr Stamatios Karavolos, Clinical Research Fellow in Reproductive Medicine.

**Please initial boxes below:**

<b>Statement</b>	
I confirm that I have read and understood the information sheet (version 1.0) and the consent form in relation to the above study, and I have had the opportunity to discuss it and ask questions.	
I understand that I am under no obligation to take part in the study and that a decision not to participate will not alter any treatment that I would normally receive.	
I understand that I have the right to withdraw from this study without giving any reason.	
I agree to take part in a one-hour interview that will be audio recorded.	
I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the NHS Trust and from regulating authorities where it is relevant to my taking part in this research.	
I understand that interview records may be stored for the duration of the study.	
I understand that I will not benefit financially from this research and its outcomes.	

**Name**..... **Signature**..... **Date**.....  
(of participant) (of participant)

**Signature of witness**..... **Date**.....

## Appendix C

### Invitation Letter

Newcastle Fertility Centre  
Bioscience Centre  
International Centre for Life  
Times Square  
Newcastle upon Tyne  
NE1 4EP  
Tel. 0191 2138213

Dear

**RE: Psychosocial experiences of men with fertility issues: a research project.**

Our unit is undertaking a study to evaluate the feelings and experiences of men diagnosed with azoospermia (an absence of sperm in the semen). We would like to invite you to take part in this research study that aims to advance our understanding of the impact this problem has on your day-to-day life. This will help up optimize the clinical care we provide to men with similar problems.

As part of this research, Dr Karavolos, Clinical Research Fellow at Newcastle Fertility Centre is conducting interviews with patients who have experienced fertility problems, to find out about their experiences of going through infertility care and treatment. Interviews will be audio recorded with permission but all information collected will be strictly confidential.

I would be grateful if you would consider taking part in a 1-hour interview at a mutually convenient time and place to discuss your experiences.

Please find enclosed an information leaflet and consent form if you wish to take part in the study. I would be grateful if you could complete and return the enclosed form with the consent to Dr Karavolos, at the address below.

If you require any further information, please do not hesitate to contact Dr Karavolos on the telephone below.

Yours sincerely,

---

Study: Psychosocial experiences of men diagnosed with infertility.

I do /I don't wish to take part in the study.

Name:

Address:

Tel:

Email:

Please return the completed form to: Dr S. Karavolos, Newcastle Fertility Centre at Life, Times Square, Newcastle upon Tyne, NE1 4EP.  
Tel 0191 2138213

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Version 1: 28.4.13

## Appendix D

### Poster with information for the recruitment of participants

The Newcastle Upon Tyne Hospitals   
NHS Trust

Newcastle Fertility Centre at 

## Genetic investigation and psychosocial experiences of men with fertility issues: A research project

- **Azoospermia (an absence of sperm in the semen) is a distressing problem for couples, but the reasons for it are poorly understood.**
- **Little is known also about the impact of this problem on the couples that it affects.**
- **We would like to invite you to take part in a research study that aims to advance our understanding of the causes of azoospermia and the impact this problem has.**
- **If you are interested in taking part please ask at the reception desk or use the contact details below.**

For further information contact: Dr Stam Karavolos or Miss Raveen Sandher, Clinical Research Fellows, Newcastle Fertility Centre, International Centre for Life, Times Square, Newcastle upon Tyne, NE1 4EP, Tel 0191 2138213

Version 1:  
15.3.13

## Appendix E

### Semi-structure interview guide

Version 3: 24.7.13

**Study title:** Psychosocial experiences of men with infertility

#### **Semi-structured interview guide**

(Note: this is an indicative guide only; the conduct of any individual interview will vary as is the norm for semi-structured interviewing. Initial interviews will feed ideas into later interviews to discuss)

#### **I. Introduction to the project**

##### **a) Introduction and purpose of the project**

Thank you for agreeing to take part in our research.

*[Introduction of myself, my role in the study and my supervisors in the project and sponsors of the study].*

As you will know, many considerations and decisions need to be taken regarding the diagnosis and treatment of severe male factor infertility.

Our study mainly focuses on the psychological and social experiences of men diagnosed with azoospermia (an absence of sperm in the semen), and have to consider treatment options. I would like to talk to you for about an hour about how you felt when you found out about this problem, and about how you came about making decisions regarding your treatment.

We hope to understand how men feel about the diagnosis of male factor infertility. The findings of this study might influence the organization of treatment and support services locally and nationally.

##### **b) General structure of the interview**

As I said, most interviews last for about an hour but it's up to you how much you want to say and for how long. I will have an interview guide in front of me to remind me of the key points that I would like to cover.

I might, from time to time, refer to this to keep myself on track.

##### **c) Content of the interview**

We are aware that you have gone through difficult times so if there is anything you don't want to talk about just say. We want to know your experiences of male factor infertility and the implications that this had on you and your close family, in the hope that we can learn lessons and help other patients in the future. We also want to know what factors influenced your decisions at different stages of your investigation and treatment.

##### **d) Consent to audio tape the interview**

In order to ensure we don't make mistakes in interpreting what you tell us, I would like to record our discussion. Later on the recording will be transcribed on to paper and your personal details removed, so that all the information remains confidential.

I can assure you, that this interview, and whatever views you express today, is not going to alter your relationship with the doctors in the fertility clinic, and would not influence your treatment.

Only myself, and my supervisors will have access to this information.

As I said earlier, if there are any questions that you don't want to answer, just say so, and remember we can stop the recording or even the interview any time, if you wish so.

Do you have any questions?

I will now get the recorder set up and we can start the interview.

## **II. Demographic details**

*I would like to ask you a few questions about you. This will help me build up a picture of the different background of people that will take part in this study.*

- a. May I ask your date of birth?
- b. What is your ethnicity or nationality?
- c. What is your occupation?
- d. Do you have a religious faith?

*Thank you.*

## **III. Early concerns- realising there is a problem**

*Can we now talk about the first time you realised there might be a fertility issue;*

- a. Can you remember when you and your partner first realised there might be a fertility issue?
- b. Did you realise suddenly or did the problem build up over months/years?
- c. Was there any pre-existing condition that caused you concern?
- d. Did you ever think that the problem could lie with you, rather than your partner?
- e. What did you and your partner do when you realised that it was taken so long to conceive?

#### **IV. Referral for further investigation/diagnosis**

*Can we now talk about your referral to our unit to have further investigations?*

OR *tell me about your referral to our unit.*

- a. How did you feel about having to visit a fertility clinic?
- b. Can you explain what it was like to go and have your SA done?
- c. Did you expect to have a physical examination? What was it like?

#### **V. Psychological reaction to confirmed diagnosis**

*I would now like to ask you a little bit more about how you felt when you first found out about the diagnosis.*

- a. How did you feel when it was confirmed that there was no sperm in your semen?
- b. What did it mean to you to have a fertility problem?
- c. What did you think to be the cause? Why?
- d. Did you ever think that lifestyle choices may have contributed to this?
- e. What did the Dr say might be the cause of your infertility after all the investigation?
- f. How did you feel about not having an explanation for the lack of sperm in your semen? (if applicable)

#### **VI. Help-seeking behaviour**

- a. What would have helped you come to terms with your infertility?
- b. Where you offered any counselling?
- c. Did you seek any further help?
- d. Did you know anyone else who had the same problem?
- e. Did you ever feel reluctant to ask for help/counselling?
- f. Did you feel that your emotional/psychological issues were recognised adequately addressed by your doctor/nursing staff?

**VII. Impact of diagnosis on self image/sexual function/libido/erectile dysfunction**

- a. What effect did the diagnosis have on how you felt about yourself?
- b. Did it impact on your everyday life?

**VIII. Impact on relationships- partner/ family/ friends/colleagues**

- a. Who did you tell about your infertility?
- b. How did your partner feel about this?
- c. How did the diagnosis of infertility impact on your relationship with your partner?
- d. (Did the diagnosis result in any conflict with your partner?)
- e. What impact do you think the diagnosis had on your partner?
- f. Did you feel concerned about your partner's emotional reaction to the diagnosis?
- g. How did you help your partner come to terms with this?

**IX. Coping with infertility**

- a. How did you feel about asking for help?
- b. Did you ever feel the need for more professional help? e.g. counselling
- c. From whom did you feel comfortable seeking professional psychological support? (from your doctor or professional counsellor?)
- d. Were you, at any point, reluctant to discuss the problem with your partner?
- e. Did you at any point feel that you wanted to talk to your doctor **without your partner being present**?
- f. Did you believe that you can overcome your feelings alone?
- g. Did you feel embarrassed to ask for help?

## **X. Deciding the next steps in fertility treatment (IF APPLICABLE)**

*Let's now talk about what went through your mind when you took the decision to proceed with treatment.*

- a. How did you feel about undergoing surgery for sperm retrieval?
- b. How did you feel about the possibility of finding no sperm for treatment after surgery?

*The possibility of having to use donor sperm is a big step because it has far-reaching implications for your whole family and, of course, your child.*

- c. Can you remember when the option of donor sperm or adoption was first mentioned?
- d. How did you feel when the option of donor sperm use was brought up?
- e. At what point in your treatment did you have to decide whether to use donor sperm or not?
- f. What was going through your mind when you were trying to decide about whether to use donor sperm or not?
- g. How long were you given to decide?
- h. How did your partner feel about using donor sperm?
- i. How did your partner help you make a decision?
- j. Was there anyone else that had an important influence in your decision making regarding donor sperm use?

## **XI. Questions for those who had successful treatment**

- a. How did you feel when you found out that your operation was successful in retrieving sperm?
- b. Did this count as success for you?

## **XII. Questions for those who had unsuccessful treatment**

- c. How did you feel when you found out that there was no sperm retrieved after your sperm retrieval operation?

### ***Further questions***

- a. Are there any other issues/experiences that you would like to share?
- b. Is there anything else you would like to ask at all?

*Thank you for taking part in the study.*

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