

# The Experience of Infertility Treatment: The Male Perspective

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# The Experience of Infertility Treatment: The Male Perspective

#### Abstract:

Current research surrounding infertility is focused primarily on women alone, thus removing men from the fertility equation. However, alternative research has indicated that although men also experience infertility, there is a paucity of research on men. Therefore, very little is understood about the experiences of infertility from the male perspective. This study adopted a qualitative approach in an attempt to explore the infertility experience from the perspective of men. Fifteen men who had experienced infertility were interviewed to explore their experiences. Interpretative Phenomenological Analysis was used to analyse the data. Five superordinate themes were developed, these included: the influence of society on infertility, feeling unacknowledged, natural conception verses assisted conception, emotional reactions and improving the infertility experience. The findings of this research indicated that men experience infertility as a mentally, physically and socially demanding condition. Comparisons to previous research have been made and future research is proposed.

#### **Introduction:**

Infertility impacts widely with an estimated 1 in 7 heterosexual couples in the UK experiencing infertility (NICE Guidelines, 2014). Extended literature reviews have indicated that research has focused primarily on women; this may be due to the fact that women are generally believed to be at the center of infertility treatments and causes. However, it is important to acknowledge that infertility is a condition, which impacts both men and women. The World Health Organisation (Zegers-Hochsclid et al, 2009) defined infertility as an

inability of a sexually active, non-contracepting couple to achieve pregnancy after one year indicating that infertility involves more than one person and not just the female.

Men are generally understudies in this topic area. Most research discussed in Greil and colleagues (2010) literature review used females as its focus, thus leaving the males perspective of infertility understudied in comparison. A long-standing belief has been that infertility causes women higher levels of stress in comparison to their partners (Jordan & Revenson, 1999). Another study showing that infertility is stressful for women was conducted by Ozkan & Baysal (2006) who used a mixed method design to explore the emotional stress in infertile women and found that depression and anxiety was high. These studies show that infertility has a negative impact on women however; there is little research on men. This focus on women is surprising as the Infertility Network UK (2014) found that approximately half of the couples experiencing infertility have issues, which are associated with the male party.

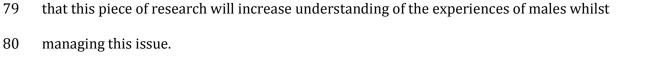
It is difficult to gain an insight into how men experience infertility, due to the minimal amount of research surrounding male factor infertility. A study by Dooley and colleagues (2011) shows that another reason that little is known about men's feelings is that male factor infertility is perceived as stigmatizing by men, thus they very rarely disclosed their diagnosis to or discuss their feelings with others. However, the little research that is available has indicated that infertile men have reported feeling a sense of shock and perceptions of abnormality in regard to their infertility diagnosis (Dooley et al., 2011).

Societal attitudes have also been found to be an influential factor for those experiencing infertility. For example, perceptions of masculinity can influence infertility treatment for men as being viewed as masculine includes not just feeling like a man but also experiencing fatherhood (Hinton & Miller, 2013). Social norms can also influence the acceptance of using

alternative reproduction solutions such as adoption and sperm donations (Turner & Nachtigall, 2010; Inhorn, 2006). There are also reports that the perceptions of men are that male factor infertility is considerably more stigmatizing in comparison to female factor infertility (Wischmann & Thorn, 2013), where men experience shame when faced with infertility. However, these repercussions were considerably stronger for those residing in countries were the uses of assisted reproductive technologies are deemed as taboo for example, in Pakistan (Khalid & Qureshi, 2012).

Social support has been found to be beneficial when adjusting to an infertility diagnosis (Martins et al., 2011). Although social support may be a benefactor for women, there is no evidence to show the effects for men. This may be due to the social stereotype that men do not wish to discuss their problems however; this is yet to be addressed. Support from medical professionals is equally important. The relationship between infertility related medical professionals and patients has also been shown to have issues. Both men and women have reported finding the interaction with their medical professional to lack respect, support, comfort and information. They have also reported wanting to feel like 'human beings' when receiving fertility care (Dancet et al., 2010). Another study conducted by Mikkelsen and colleagues (2012) found that men felt as though the medical professionals solely communicated with their partners, highlighting a potential inequality between men and women experiencing fertility treatment.

These studies mostly show the experience of infertility from the women's perspective and the majority of this research has failed to consider the impact infertility has on men. However, those that do tend to lack depth and potential for improvement. This has resulted in a lack of knowledge of the experience of male factor infertility. This study aimed to address this issue. A qualitative approach was taken to explore this area of the infertility experience. It is hoped





#### **Method:**

<u>Design:</u> A qualitative design using an interpretative and phenomenological approach was used in this study to gain an in-depth insight into the experiences of infertility for men. The data was analyzed using Interpretative Phenomenological Analysis (IPA).

Participants: Fifteen men who had either received treatment themselves or were acting as support for their partners were recruited for this study. The types of treatments engaged in varied between participants. Participants were recruited through the use of adverts in both international and national online Infertility support forums; additionally a snowballing technique was used where participants mentioned the study to friends and family who then contacted the researcher in an attempt to participate. Interviews were the chosen method of data collection as they allow for in-depth information regarding experiences and perspectives over a specific topic to be collected (Turner, 2010).

Data Collection and Interview Schedule: Due to the sensitive nature of the topic, interviews were deemed beneficial in comparison to other methods such as focus groups, this was due the fact that interviews allowed for a rapport to be developed between the researcher and participant, and as a result made discussing a sensitive subject less daunting. The interview schedule consisted of twenty-four items and followed an open structure, to allow for a deeper insight to be gained. Examples of the items used included 'talk me though your journey though infertility'. The questions used within the study were based on the gaps found in the literature. They addressed various stages of the treatment process, such as the support offered and the interactions between the participants and their health care professionals.

Procedure and Analysis: Each interview was recorded and lasted just over an hour; the data was then transcribed verbatim. The data was analyzed using IPA as it aims to explore the process though which participants attempt to make sense of and understand their experiences (Smith et al, 1997). The analysis followed the steps for the IPA proposed by Smith and colleagues, which involved coding and the grouping of themes after in-depth familiarization with the data thus, allowing the researcher to further understand the experience of infertility from the participants' perspective.

*Ethics:* The study was granted ethical approval by the Brunel University, London ethics committee.

#### **Results:**

Interpretative Phenomenological Analysis revealed five superordinate themes followed by multiple subthemes.

| 145 | Themes                     | Subthemes                                      |
|-----|----------------------------|--|
| 146 | 1. Influence of society    | 1.1 - Masculinity                              |
| 147 | on Infertility             | 1.2 – Perceived stigma                         |
| 148 | 2. Feeling                 | 2.1 – Relationships with medical professionals |
| 149 | Unacknowledged             | 2.2 - Unsupportive family                      |
| 150 | 3. Natural Conception      | 3.1 – Genetics                                 |
| 151 | versus Assisted            | 3.2 – Beliefs towards adoption                 |
| 152 | Conception                 |  |
| 153 | 4. Emotional reactions     |  |
| 154 | 5. Improving the Fertility | Experience - The males perspective             |

1. Influence of society on Infertility

Participants frequently discussed their perceptions of societal norms and attitudes and also commented on how they felt these attitudes influenced their own experiences. Two subthemes were developed under the influence of society; masculinity and perceived stigma.

### 1.1 - Masculinity

When discussing masculine identity, participants frequently referred to the perception of needing to be compliant with the label of masculine. These beliefs included feeling less of a man for not being able to impregnate his partner.

"I'd say mentally it was certainly something you know that was taking its toll on me, something that was making me feel...you know when you can't impregnate your wife, it makes me feel like less of a man. It makes me kind of feel like less of a person and that's something, which is core to your humanity....it's something that's kind of being a goal to your existence" (4).

In this quote alone, it is apparent that the participant had internalized multiple social and masculine norms. This participant makes it clear that his inability to impregnate his wife left him feeling 'less of a man' which is a clear social belief which he had internalized. From the perspective of the participant, it is evident that the internalization of the social belief has had a negative impact on his perceived masculine identity. This was common amongst a vast majority of the participants. In addition, the participant describes the ability to conceive as a goal to existence, thus indicating further his perception of his role as a male. It also highlights

how life-encompassing infertility actually is. This quote, similarly to others also highlights the participant's strong desire to want to be able to conceive their own children.

The quote from participant three below highlights the embarrassment males experience when faced with infertility. This sense of embarrassment was evident across all the participants.

"Imagine if a guy in an office was saying – oh my sperm won't fire- he'd be the butt of every joke possible! That sort of thing does hurt male egos, it does and can scar them emotionally" (3).

The fact that the individual uses the word 'scar' can be seen to imply something of a traumatic nature. It may also be symbolic of a long lasting imprint of the negative feelings and emotions that accompany infertility. This quote also hints towards a sense of stigma however, the fact that the participant attempts to incorporate humour could also further indicate that a male unable to fulfill the perceived societal role of a man could be seen as a joke in itself. The following quote extends the traumatic nature of infertility, as the inability to conceive is being depicted as a 'dirty secret', with the participant challenging it.

"I think it's not a dirty secret. I think that's the first thing that men have to realize is that it's not a dirty secret to not be able to conceive" (10).

This quote shows an emotional reaction, but in the sense of embarrassment. The participant's choice of words to describe the inability to conceive as a dirty secret could be an indication that his personal experience was coined with elements of embarrassment and shame.

Alternatively, it can also be viewed as an extension of social and stigmatic norms.

| 206 |   |
|-----|---|
|     | .2 – <u>Perceived stigma</u>  |
|     | .2 – <u>rerceiveu stiginia</u>  |
| 208 |   |
| 209 | Some participants also reported feeling a sense of stigma whilst engaging in treatments. This |
| 210 | sense of stigma overlaps masculine norms as it was evident that individuals began to          |
| 211 | internalize certain norms and as a result ended up stigmatizing themselves.                   |
| 212 |   |
| 213 | "The reason I wouldn't want to tell someone was this weird stigma in our culture that, if a   |
| 214 | man doesn't produce sperm, he's less of a manyou never want to be less of a manI              |
| 215 | didn't want them to think less of me for not being able to produce sperm" (8).                |
| 216 |   |
| 217 | This quote encompasses the participants perceived stigma as well as the recurring perception  |
| 218 | of being less of a man. It also hints towards a strong aversion to disclosing their fertility |
| 219 | struggle.   |
| 220 | struggle.   |
| 221 |   |
| 222 | 2. <u>Feeling unacknowledged</u>  |
| 223 | Participants expressed that they felt excluded when embarking on the journey of infertility   |
| 224 | treatments. In addition, they reported feeling dismissed from the process. Two subthemes      |
| 225 | were developed as part of this theme: relationships with medical professionals and            |
| 226 | unsupportive family.  |
| 227 |   |
| 228 | 2.1 – Relationships with medical professionals.   |
| 229 |   |
| 230 | The participants frequently reported feeling that their relationship with the medical         |

professionals involved in their care was weak. The participants reported feeling dismissed

from the treatment process and some even reported feeling a sense of blame they felt from their medical professionals as told by participants six, eight and ten.

"The first time we met with the urologist, he asked if I had done steroids and then he asked again in the same room with my wife...and when it was just him and myself. So he was like 'seriously have you done steroids?' I mean it was a very weird conversation, almost as if it was like he was asking me 'well how did you screw this up?'. You know there was no sort of support or consoling" (6).

"He asked me if I smoked weed like 20 times, "do you smoke marijuana?" no, and I actually don't. No I don't – "Are you sure you don't?" – Yes! I'm positive – "not even once?" – No! Not even once! (8).

These two quotes illustrate a sense of blame, which was felt by the participants. This sense of blame was further highlighted by the fact that the medical professionals asked the same questions repeatedly, almost as if they didn't believe the participants answers. This repetition of questions clearly made the participants feel uneasy. A lack of support is also emerging.

"When I was having a conversation with her (urologist) about the decisions that we were making about like this is it after this we're not going to try, I think we're going to go for adoption or something like that and she (urologist) interrupted, she wasn't looking at me, so she interrupted and responded to a question my wife asked in the appointment earlier...she (urologist) would never look at me" (10).

This quote gives an example of where these feelings of dissatisfaction originate. The dismissive nature can be seen through the urologist clearly ignoring the participant's

contribution. However, the fact that the urologist refers back to a question previously asked by the participant's wife also provides support for literature which states that women are at the center of all fertility treatment. The fact that the participant also commented on the urologist's body language shows they felt dismissed in multiple ways. Many of the participants reported that conversations held between the medical professional and the couple was all directed to the wife. This was the same with medical correspondence as participant ten mentions below.

"Letters are not addressed for the two of us, so everything is Miss (wife's name) and not (wife name and husband name). Even the bills aren't addressed to me. When you make appointments, even if it's for both of us, even if I have to give my sample it was my wife's appointment. Its like you are the plus one but you're not really considered" (10).

Participant ten explains he felt like a plus one, indicating that the participant felt like an optional extra. The fact that his appointment to give his sample is addressed to his wife shows the lack of acknowledgement of his role in the treatment.

## 2.2 – <u>Unsupportive family</u>

Family support was found to have a protective effect on women experiencing infertility (Martins et al., 2011). The results of this study may indicate that this is so for men too.

Participants five and six below give an account of their interactions with their family and how they were left feeling unsupported. It is important to consider that the idea of support is indeed subjective and personal for each participant. However, an example would include simply having the opportunity to talk to someone who the participant trusts.

"Most people did seem like they were uncomfortable about you know. Especially our parents. So both sets of parents, mine especially didn't particularly want to talk about it"

(6).

"You would think that my sisters and my mum and dad would have a little bit more

"You would think that my sisters and my mum and dad would have a little bit more interest and ask some questions...It's weird that nobody really seems to care what our situation is and how difficult is really is" (5).

Both these quotes show families failed to offer support. This lack of support from family
 members may be due to the reluctance to discuss a personal issue and shows the stigmatized

beliefs and perhaps a lack of education around the topic of infertility. Overall, the quotes indicate that men do wish to discuss their struggles but find it hard to find someone with

whom to talk.

# 3. Natural conception versus Assisted conception

This theme shows how participants had a mixed reaction to the use of alternative reproduction methods. This theme also showed the motivation for engaging in the painful and alienating process.

# 3.1 - Genetics

For many individuals the concept of passing down genetic make-up and reproducing their own child was imperative. This led to mixed emotions towards the use of donor sperm.

"There was this thing that I just wanted it to be my child, I didn't want to raise a strangers child, I didn't want to think about having to use donated sperm...everyday you're sort of reminded about...you know you're raising the child but its still not your genes, it's still not a part of you" (6).

This quote highlights many of the opinions expressed by the participants. It is clear that the participant not only wants a child, but is also haunted by his infertility struggle. The fact that he feels as though the use of sperm donation would serve as a constant reminder of his struggle may even indicate that the using sperm donation would make him feel like less of a man.

#### 3.2 – Beliefs towards adoption

In line with the beliefs towards sperm donation, adoption as common as it may be was not a popular method.

"What's difficult is that I've noticed that a lot of people will say at least you can always do adoption and yeah you can, but it's not the same thing as having your own child!...Adoption, we're super scared of it, there's a lot of things that make us nervous.

Will the parents want the baby back? Will the child when it grows up, will it was to abandon us and go back to its birth parents?" (3).

This participant mentions something, which has been universal across the participants; the idea where adoption is always an option. For many of the participants, hearing others'

the underlying themes in this quote was the idea that adopting a child is not the same as

comments about adoption was received as a rather insensitive comment. Once again, one of

having your own. The participant also addressed some of the anxieties he has about adopting, in particular the fear of being abandoned by the child later on in life.

4. Emotional Reaction

This theme highlights the reported emotional repercussions infertility had on these participants. Contrary to the common belief that men do not like to discuss painful experiences they have gone through, many of them opened up to how infertility impacted them emotionally. The following quote shows how close to the surface the emotions can be.

"It's really tough, I'd walk past a children's playground and get tears, I get quite depressed...Even when you're watching TV and someone gets pregnant you get upset and you have to turn it off" (9).

This participant voiced how much of an impact infertility has had on his life. This quote also portrays how life encompassing infertility struggles are. The fact that the participant reported feeling a sense of depression indicated that the emotions felt by the individual were strong. This idea of depression was a common theme found within the responses of the participants. The following quote shows how a participant felt suicidal during his infertility experience. This may well be an extension of the depression experienced.

"From a purely biological standpoint the purpose of life is to reproduce and pass on your genetics and so here I am finding out that I am unable to pass on my genetics and the biologist in me says 'you are worthless, you have no purpose of living'. I was on the verge of suicide for a while" (8).

5. <u>Improving the fertility experience – the males perspective</u>

This theme identifies suggestions made by the participants to improve the infertility experience. Participant eleven shows an awareness of social awkwardness that may be experienced by men when discussing their issues. A potential solution was also provided.

"I think males, they should give males an opportunity to speak to the doctor without anyone else present, because I bet you most males would be too proud to say something they are afraid of or concerned about during this process" (11).

Participant nine speaks of being warned of the emotional roller coaster that awaits the infertile man and some preparation for this would have been beneficial.

"If someone sat down and said you're going to go to a doctors office and one minute you're going to feel really depressed, the next minute you're going to feel a bit of hope"

(9)

An underlying theme in both quotes is that men do wish to talk! Both of the quotes also deviate from the societal belief that men don't wish to discuss their problems. Perhaps giving men an opportunity to speak to their fertility specialist independent from their partner may help bridge the perceived weak relationship between males and their medical professionals. It may also provide men with the opportunity to be heard and as a result can be seen to improve their fertility experience.

#### **Discussion:**

This study aimed to gain an in-depth understanding of this under researched area. The results show that the infertility experience for men was a predominantly negative experience, where males reported feeling ignored, stigmatized and isolated. This study also challenged the social norm that surrounds the idea of men not wanting to discuss their issues and found it to be incorrect for some men. Previous research hinted towards the idea that infertility is difficult to deal with for men however, what differentiates this study to others is the depth of the findings which have emerged from them.

The first theme demonstrated how the existence of social norms such as masculinity and stigmatic beliefs were perceived to influence the experiences and perceptions held by the participants. A majority of the participants disclosed how the presence of infertility caused them to feel like less of a man. This was also found in a study conducted by Hilton & Miller (2003) and Wischmann & Thorn's (2013) study, which found a diagnosis of male factor infertility, was experienced as more stigmatizing in comparison to any other fertility diagnoses. This idea of feeling like less of a man can be seen to extend and overlap into the third theme of Natural conception versus Assisted conception showing that using alternative reproductive methods was not popular due to the perception that the child would not biologically belong to the participant. This also supports Hinton and Miller (2003) who concluded that masculinity involved feeling like a man and also being a father. It is also important to acknowledge that the participants did indicate their avoidance towards alternative methods, but also provided insight into why they were avoidant of these methods. This may be beneficial for healthcare professionals to consider when suggesting alternative methods. Overall, previous research indicated that infertility is stigmatizing experience and difficult to deal with both socially and personally. However, the findings of this research show how all of these influences appear to interact with one another highlighting how difficult dealing with infertility really is.

Another predominant finding was the lack of acknowledgement that males felt from both the medical professionals and also members of their family during the infertility process. This theme occurred with the majority of the participants as they reported the numerous ways in which they felt ignored. Thus, supporting Dancet and colleagues' (2010) study, which identified similar factors, which patients would like to see being implemented into fertility care. One of the factors being support, as seen in the results above men also wanted to be supported when experiencing infertility and another factor being the involvement of the partner within the fertility process, as the results of this study explicitly show how men feel they were dismissed from the treatment process, therefore agreeing and extending previous research. The findings highlight and also offer support for Mikkelsen and colleagues (2012) who found that men felt as though the medical professionals only communicated with their partners.

The findings also provided support for Martins and colleagues (2011) who concluded that social support could be seen as beneficial to adjusting to the infertility diagnosis. However, this would need to be researched further, as the participants in this study reported a lack of social support, but suggested they would have liked social support. Once again, this study provides new evidence on how men experiencing infertility would like to be supported by healthcare professionals.

The third theme explored the debate between scientific assisted reproduction and alternative reproductive methods. Many participants were against the use of adoption and sperm donations due to a sense of kinship and the belief that with the use of these solutions the child

will not be, in their opinion, their own child. The findings of the current study run parallel to those of Turner & Nachtigall (2010) and Inhorn (2006) who also found that individuals may avoid adoption and sperm donation due to stigma and also the perception that the child is not their own. This perception appeared to be dominant.

A vast majority of the current literature has focused on the psychological repercussions infertility has been on females, thus the findings of this current study indicate that this area requires further investigation, as men have reported experiencing a range of psychological difficulties during their fertility journey. The themes discussed above show the psychological factors of infertility for men, where feelings of depression, isolation due to the lack of support and shame due to the threat of the participants masculinity. Participants in this study report feeling depressed and in some cases suicidal over their situation, as well as illustrating how life-encompassing conception really is. A simple thing such as walking through the park or watching a television program can be seen as difficult when facing infertility due to the emotional cues they may initiate. Depression can be experienced in infertility and is shown in the findings of Ozkan & Baysal (2006) who suggested that depression and anxiety was high among infertile women. These negative experiences associated with infertility are factors that should be considered by health professionals for interventions.

The fifth and final theme shows how not only do these results highlight the difficulties infertility presents, they also offers potential suggestions and solutions that can be utilized to improve this issue. For example, making healthcare professionals aware of the attitudes towards alternative reproduction methods and ensuring they acknowledge both members of the couple during discussion. The participants in this study also requested equal methods of support in the form of independent meetings with consultants.

Although the study successfully recruited fifteen participants, the limitations of this study include, the variation in the cause of the infertility. Different etiologies are likely to influence the degree of acceptance and attitude towards infertility and future research could investigate these differences. Ethnicity was also not measured in this study and so different cultural beliefs are not accounted for. This study also only recruited heterosexual men and although generalizability is not the aim of qualitative studies these results give an account of the experiences of a group if men which are indicative of what other men feel.

Overall, the results of this study are important as they give voice to men experiencing infertility and the perceived impact of living with infertility. These findings shed light on an under-researched area and allow an understanding of the experience of men.

The findings also provide foundations for future interventions especially with regard to making this experience more acceptable for men.

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