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Exploring the lived experiences of infertility treatment and care by involuntarily childless women

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Abstract

This study explored the lived experiences of fertility treatment and care by South African women with infertility . A total of 21 women from different age and ethnic groups (age range = 26 to 41; whites = 53%, coloured = 47%) were interviewed for the study . The women responded to semi-structured interviews on their lived experiences of fertility treatment and care whilst undergoing treatment . The data were analysed using thematic analysis . Four main themes were identified in the study; including: lack of compassionate care from treatment care providers, the need for infertility clinics to integrate psychosocial support care, a need for continuing education for fertility staff, as well as financial support resourcing . Participants expressed a need for health care staff at fertility clinics to be more attentive to their emotional and psychological needs . In addition, participants perceived a need for psychosocial care as a result of the distressing nature of the treatment process . The women also felt that some health care staff lacked technical knowledge about the fertility treatments and this left them deprived of crucial information . The costly nature of fertility treatment presented as an added burden for participants . Overall, participants seemed to require a more individualised and patient centred form of fertility care .

Introduction

In Africa, infertility prevalence rates range from 30 to 40% (Kamel, 2010). This is a major social concern for families in the patriarchal, pronatalist African societies in which women are valued for their fertility. In this cultural setting, women who are involuntarily without children may find themselves ostracised for lack of motherhood ability by reason of infertility (Ali et al., 2011; Boivin & Kentenich, 2002; Deribe, Anebir, Regassa, Belachew, & Biadgilign, 2007; Kamel, 2010; Mishra & Dubey, 2014; Ombelet, Cooke, Dyer, Serour, & Devroey, 2008; Winkelman, Katz, Smith, & Rowan, 2016). For this reason, women may compulsively seek fertility treatment so that they are totally engulfed by the need for fertility (Inhorn, 1996; 2002; 2003; Inhorn & Buss, 1994; Inhorn & Van Balen, 2002; Gerrits, 1997, 2002). In vitro fertilisation and Embryo Transfer (IVF-ET) is the last treatment option available to women. This fertility treatment procedure often requires mental and physical endurance with regular doctor's appointments, and significant financial costs. In brief, the treatments can be distressing.

Women trying to overcome infertility have few options available to them. They can pursue fertility treatments and Advance Reproductive Technology (ART), adopt a baby, keep trying to fall pregnant naturally, or resign themselves to a life without children. If a woman wants a biological child, she can pursue fertility treatment such as IVF-ET or artificial insemination, surrogacy, donor assistance, or keep trying to fall pregnant naturally. Infertile women who seek ART are condemned if they do and condemned if they do not. In not choosing to pursue ART, they may be perceived as being 'selfish' and 'immature' and effectively choosing to remain childfree; whereas in choosing to pursue ART one is deemed to be 'playing God' by taking matters of procreation in one's own hands. Childfree women in pronatalist societies endure severe stigma and disapproval (Bihma & Chadwick, 2016). Choosing to be childfree is defined in the literature as the conscious decision, desire, and plan not to have children (Agrillo & Nelini, 2008). Women who choose to relinquish motherhood for personal advancement have been found to view motherhood as potentially disruptive and counterproductive to attaining aspired-to goals (Gillespie, 2003; Agrillo & Nelini, 2008). Therefore, not choosing ART is in essence choosing to remain childfree and these women are often labelled as self-regarding and puerile. This study sought to explore the fertility treatment experiences of South African women with involuntary childlessness from suspected infertility.

Method

Participants and setting

Twenty-one women were recruited for the study. The women ranged in age from 26 to 41 years, with the average age being 30 years old. Inclusion criteria were that the women had to be married or at least in a committed relationship, and presenting with primary infertility, as well as having undergone at least two rounds of IVF-ET. The women were sampled utilising snowball techniques. Four of the participants were Muslim, while the remaining 17 participants were Christian in religion. Furthermore, 19 of the participants had full time employment while only two of the participants were unemployed.

Procedure

Ethical approval to conduct the study was obtained by the University of the Western Cape Ethics Committee . All of the participants voluntarily participated in the study . The participants were assured that all information provided would remain confidential and that their identity would remain anonymous . Participants were also informed that they have the right to withdraw from the study at any time and given the assurance that any questions deemed too difficult or too personal to answer could be omitted . A psychologist was available to the participants; however, none of the participants opted for this service .

The participants were invited to a briefing session whereby they were informed about the study aims, procedures, and ethical considerations. Since the aim was to recruit a diverse sample, further consideration was given to the distributions of ethnic (black, white, or coloured ancestry) groups, the participants' mother tongue (i.e. Afrikaans, English, and Xhosa), and religion (Christian, Muslim, or Hindu).

Data collection

The women responded to semi-structured individual interviews and shared their experience of infertility care, the kinds of support they received, and needed undergoing treatment.

An interview guide was pre-tested to ensure content validity. The duration of the interview was approximately one hour. To ensure trustworthiness of the data, a few elements were undertaken; for example, the researcher transcribed the interviews verbatim and asked the participants to read through the transcriptions and confirm their responses. The researcher also consulted with an independent coder to assist with identifying emerging themes. The independent coder agreed upon the themes found by the researcher and identified corresponding emerging themes. The researcher used an audit trail to keep account of all records and activities throughout the research process.

Data analysis

Data were analysed for themes applying the method proposed by Braun and Clarke (2006). Preliminary themes were identified and finalised applying coding, interpretation, and drawing of conclusions.

Findings and discussion

Four primary themes emerged from the data: lack of compassionate care, integrating psychosocial support care into infertility care, provider preparation issues, and financial support resourcing. These themes are considered below.

Theme 1: Lack of compassionate care from doctors and nurses

All of the participants expressed frustration about the lack of compassionate care from the doctors and nurses that tended them whilst they were undergoing treatment. They perceived the lack of attention to their psychological and emotional needs to have been particularly distressing:

I was actually very emotional that time and he [the doctor] just sat there looking at me. He did not know what to say to me (Participant 3, white, 31 years old).

[I wanted] just to be asked... "Are you coping?" That would be nice...but he [didn't ask] ...he thinks he knows that I'm coping...I think...but it would be nice to think that he is concerned about me emotionally as well (Participant 8, white, 36 years old).

Of three nurses only one nurse is quite soft and gentle and we have a good laugh and a joke. The other sisters are very formal, very strict and they don't really take an interest in how you are doing emotionally. What is it to ask "How are you coping with this?" (Participant 13, coloured, 26 year old)

[When] I try to speak to him about it I can see he is blocked off and uncomfortable (Participant 11, white, 32 years old).

I don't really feel like the medical staff there worry too much about their patients, they just there to do their job and that's it (Participant 19, coloured, 34 years old).

Fertility patients attach importance to a number of dimensions of patient-centeredness (Dancet et al., 2010). The Picker Institute (1993) identified eight dimensions of patient-centred care (PCC): (i) respect for patient preferences, values, and expressed needs; (ii) information, education, and communication; (iii) coordination and integration of care and services; (iv) emotional support; (v) physical comfort; (vi) involvement of family and friends; (vii) continuity and transition; and (viii) access to care and services (see also Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993; Gerteis, Edgman-Levitan, Walker, Stoke, Cleary, & Delbanco, 1993). PCC presents as a multidimensional concept and is a main determinant of care quality. Organisations that provide PCC report better patient outcomes (Berghout, Van Exel, Leensvaart, & Cramm, 2015). The dimensions of PCC assist in ensuring that patients feel valued and that their needs are emphatically acknowledged. For patients undergoing IVF-ET such characteristics are perhaps particularly useful given the psychologically taxing nature of the treatment.

Theme 2: Integrating psychosocial support care into infertility care

About 86% of the participants identified the need for counselling or information sessions to what to expect during and from treatment as well as infertility in general; thereby highlighting the need for psychosocial support. Some of these responses are listed below:

Yes on a few occasions my doctor would encourage me to talk to someone like a counsellor or psychologist but did not refer me, I know it would have helped me a lot at the time (Participant 15, coloured, 28 years old).

[IF] fertility clinics should provide patients with emotional support like counselling and it will make a huge difference (Participant 4, white, 31 years old).

I think there should be support groups based at the fertility clinics (Participant 10, white, 38 years old).

It would really be helpful to talk to people who have been through all this. It would be nice to talk to someone about their experience and to ask questions and get guidance it would really make a big difference (Participant 16, coloured, 39 years old).

The doctors should give lectures and explain to patients and potential patients what the different treatments entail and also explain the different causes to us, sometimes its all very confusing and you hear different and contradictory views from various people (Participant 11, white, 32 years old).

Infertility is happening more and more these days. I believe that if we educate women about infertility in the early stages. Infertility can be decreased. Infertility Awareness programmes are essential for a woman's development (Participant 3, white, 31 years old).

The importance and benefits of integrating psychosocial support care into routine medical practice has been recognised and established by the industrialised world (Boivin et al., 2001). Two types of psychosocial care have been identified; namely PCC, and professional counselling. The former type of care is the responsibility of all the medical health practitioners whilst a practitioner whom specialises in the field of mental health provides the latter type of care. The main function of the PCC is to ensure that all patients receive the necessary emotional support that enables them to conceptualise and understand the context of treatment, adopt appropriate coping strategies in dealing with the consequences of infertility, and cope with the diagnosis (Stichler & Weiss, 2001; Stammer, Wischmann, & Verres, 2002).

Theme 3: Provider preparation issues

Approximately 72% of the women were of the view that the nursing personnel should also be equipped with knowledge and information about the various fertility treatments as they work very closely with the patients. Participants highlighted the need for continuing education on the part of treatment care providers. In this respect some of the following observations were selected and these are shown below:

They (nurses) were very professional but lacked knowledge about the IVF procedure. I asked them a few things but they could not reply. The clinic needs to have someone on available at the clinic to talk to patients and assist with queries (Participant 20, white, 33 years old).

Doctors provided adequate information but the nurses demonstrated a lack of knowledge, it is very worrying when nurses give inaccurate information (Participant17, coloured, 34 years old).

Yes it seems that the doctors provided adequate information but the nurses could not provide adequate knowledge (Participant 16, coloured, 39 years old).

The knowledge and attitude of both doctors and nurses can have a profound impact on the quality of healthcare received by patients undergoing IVF-ET techniques (Cheung, Ng, Lau, Yeung, So, & Ho, 2003). The technical expertise of nurses allow for vital information that are essential for future planning of in-house clinic training programs and also for improving the quality of care a patient receives. In Africa, where there is a growing demand for IVF-ET services, nurses should therefore be adequately trained to enable them to disseminate appropriate information on IVF-ET to patients (Obioha, Ikechebelu, Eleje, & Joe-Ikechebelu, 2014).

Theme 4: Financial support resourcing

The women expressed that the treatments should be more readily available and affordable. Furthermore, information on the infertility treatment procedures should be more accessible for infertile couples/people.

This should be advertised and I suggest the medication should be made available by subsidy to those less fortunate. The meds are too expensive (Participant 3, white, 31 years old).

I think as I said in the beginning, they need to be almost baby talk into every step that you take. There is so much unexplained answers, but I know they can't give you all the answers. You want some kind of answers. But they must remember that we are not doctors and nurses, they must explain it in everyday language (Participant 5, coloured, 39 years old).

In addition to the psychological stress that fertility patients face, there is an added financial burden. Patients incur costs for the expensive treatments as well as the use of mental health services which is often an essential source of support when undergoing treatment. This presents as more pervasive challenges in developing countries where fertility treatment is becoming more popular but is accompanied with very high financial costs (Obioha et al., 2014). The lack of financial resources prohibits the less fortunate individuals from accessing fertility treatment. Despite the financial strain, many infertile women have to live and function in pronatalist societies that value women for their reproductive abilities often leaving them feeling ostracised.

Implications for fertility treatment care practice

There have been growing concerns about modern healthcare lacking compassion for patients while failing to give the individualised care required by patients (Cornwell et al., 2012; Firth-Cozens & Cornwell, 2009; Youngson, 2008). Treatment care providers ought to consider a number of factors which emphasise the need for compassionate care. Treatment care providers have to particularly take into account that women undergoing fertility treatment are in a very vulnerable state, both emotionally and physically. This is especially true since they are going through a very demanding medical procedure that could possibly be their only chance to achieve pregnancy and experience biological motherhood (Kaliarnta, Nihlén-Fahlquist, & Roeser, 2011). This requires the establishment of an understanding and empathetic environment between the fertility treatment care providers and their patients. As an example, a great source of disappointment for women going through IVF-ET is the apparent lack of psychological support and guidance offered by the hospital or fertility staff during the process of IVF-ET (Kaliarnta et al., 2011).

Previous research has reported gaps between the attitudes and practices of both physicians and nurses in communicating possible risks to IVF-ET patients (Kadmon, Goldin, Bdolah, Farhat, & Liebergall-Wischnitzer, 2014). The use of fertility treatment care

workshops by clinics could serve as a valuable source of information on fertility issues for women . Such workshops could provide women with accurate and reliable information regarding the causes of infertility, treatment options, and what the treatment procedures entail . The lack of continuing education and training could result in patients being misinformed and thus create false expectations regarding treatment.

Moreover, few clinics have part-time or on-site mental health referral services available for women with fertility issues who might need counselling. In cases where mental health services are advised by treatment providers, these services generally come with added cost to the clients. This makes it difficult to access for those who do not have the financial means to access the services. Furthermore, in order to provide greater access to fertility treatment as well as mental health services during fertility treatment, more attempts will have to be made to make services less costly or even free, where needed.

Limitations and conclusion

There were some limitations of this study such as the use of retrospective interviews, which is subject to problems of recall (Huber et al., 2013). Nonetheless, the findings indicate that participants' experiences find agreement in the literature. Person-centred care consistently seems to be a model of choice for fertility treatment providers internationally as well as a requirement for participants involved in this study.

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