

Psychosocial Impacts of Infertility among Omani Women with Polycystic Ovarian Syndrome: A Qualitative Study

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Abstract

Background: To understand the psychosocial experience of infertility among women with polycystic ovarian syndrome in Oman.

Materials and Methods: In this qualitative study, semi-structured interviews were conducted with 20 Omani women diagnosed with polycystic ovarian syndrome (PCOS) and infertility across two fertility clinics, in Muscat-Oman. Interviews were audio-recorded, transcribed analysed verbatim and qualitatively using the framework approach.

Results: Four main themes emerged from participants' interviews related to the cultural aspects around infertility, the impact of infertility on participants' emotions, the effects of infertility on couples' relationship and self-management strategies for dealing with infertility. Culturally, women are expected to conceive soon after marriage, and most participants were blamed for the delay rather than their husbands. Participants experienced psychosocial pressure to bear children, mainly from in laws, where some admitted that their husbands' family suggested they remarried for having children. The majority of women mentioned being emotionally supported by their partners; however marital tensions in the form of negative emotions and threats of divorce were apparent in couples that had been experiencing infertility for longer time. Women were emotionally feeling lonely, jealous and inferior to other women with children and concerned that they would not have children to look after them in older age. Although women who had experienced infertility for a greater duration seemed to become more resilient and cope better, other participants described how they were using different strategies to cope with infertility including taking up new activities; whereas others admitted moving out from their in laws' house or avoiding social gatherings where the topic of children was likely to come up.

Conclusion: Omani women with PCOS and infertility experience significant psychosocial challenges given the high value placed on fertility within the culture as a result they seem to adapt a variety of coping strategies. Health care providers may consider offering emotional support during consultations.

Keywords: Infertility, Oman, Polycystic Ovary Syndrome, Psychosocial Experience, Qualitative

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Introduction

Infertility is defined as the inability of a couple to conceive after 12 months of unprotected sexual intercourse (1). Anovulation due to polycystic ovarian syndrome (PCOS) is considered the most common cause of infertility in women, accounting for 75% of infertility cases, worldwide (2). The personal and social implications of infertility are widely documented (3-5). This research also indicates that religious and/or cultural expectations and social norms around child bearing, can exacerbate feelings of stress and anxiety (6-8).

The psychosocial impacts of infertility, due to a variety of causes (not PCOS specifically) is well documented among Western populations, which report symptoms of depression, stress, anxiety, marital and social adjustments, low self-esteem and loss of control among affected women (9-12). The extent to which these findings are transferable to other cultures and PCOS-related infertility, is questionable. Qualitative studies among African women and couples highlights experiences may differ, where childlessness was argued to be responsible for marital instability, divorce, loss of social status, abuse, poverty and stigmatization (13-15).

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Research on the psychosocial impact of infertility among women with PCOS tend to be quantitative in nature and findings inconsistent (16-18). For instance, studies carried out in the US and Germany report poorer quality of life among women with PCOS, due to worries associated with their infertility (16, 19). However, findings from a study in the USA found women with PCOS reported higher depression scores and greater body dissatisfaction, mainly due to body image issues rather than infertility (20).

Exploring the cultural and contextual experience of infertility among women with PCOS is an important issue to explore in the Muslim/Arabic countries, where expectations and pressures to conceive following marriage, makes infertility an issue of a huge concern (21). A study by Schmid et al. among 655 Austrian and Muslim immigrants with PCOS reported the latter were more likely than the former to experience increasing pressure to reproduce, emphasizing the ethnic, religious and cultural differences among affected women. Further research on this is required from the East. This study aimed to understand the psychosocial experience of infertility among women with PCOS in Oman -a Middle Eastern country with Islam being the dominant religion.

Materials and Methods

Study design

In this qualitative study, an exploratory qualitative design was adopted comprising semi-structured face-to-face interviews with infertile Omani women, with PCOS. A constructivist philosophical paradigm underpinned this study (22).

Recruitment and sampling

Married infertile Omani women of reproductive age (15-49 years) diagnosed with PCOS as the cause of their primary or secondary infertility (have had a pregnancy before but with no previous live births) were targeted via infertility clinics from two government hospitals: Sultan Qaboos University hospital (SQUH) and Royal Hospital (RH) Table (1). The hospitals agreed to allow the researcher to attend fertility clinics from May 2018 to July 2018. The researcher identified eligible women from the appointment list and approached them either through a phone call or while they attended clinic. Women show an interest were provided with a detailed study information sheet. For those wishing to participate, the researcher arranged an appointment to complete the face-to-face interview.

A purposive sampling strategy was used to ensure women of different age groups, duration of infertility and duration of infertility treatment to ensure brevity and depth which helped us to achieve theme saturation. A total of 28 eligible women were identified from the two hospitals during the study period, where 25 showed interest to take part. However, obtained data attained saturation level, where no new themes were identified following preliminary analysis of the first selected 20 participants, therefore recruitment of participants did not continue beyond the 20 selected participants.

Table 1: Inclusion and exclusion criteria for the selection of patients with infertility and polycystic ovarian syndrome (PCOS)

Inclusion criteria	Exclusion criteria
Omani	Foreigner (non-Omani)
Married and in the age group (15-49 Year)	Secondary infertility with living children
Diagnosed with primary or secondary infertility (with no living children) due to PCOS	Cause of infertility other than PCOS or with male factor infertility
	Mental condition that interferes with capability to be interviewed excluding emotional-disorders such as depression, anxiety, stress disorders

Interview guide and procedure

A semi-structured interview guide was developed based on the literature and study objectives. It was started with a brief introduction and summary of the purpose of the interview and covered data management (confidentiality), reaffirmation of informed consent and outlined that participants were free to withdraw at any point. Topics then explored general experiences relating to PCOS and infertility, the psychological impact of infertility, social perceptions of infertility and coping strategies. Interviews were participant-led, which allowed the researcher to follow up on aspects discussed by individuals, accordingly. This approach helped the interviewee to better express their experience and perspectives leading to a better narrative and thus richer data. Interviews were conducted in Arabic country in a quiet room in the fertility clinic at each hospital, either before or after patients' appointments. Interviews were digitally audio-recorded and lasted 40 minutes on average (range 29-65 minutes).

Statistical analysis

Audio files were translated into English and transcribed verbatim. Transcriptions were checked for accuracy. Data was analysed inductively using the framework approach following the six steps suggested by Gale et al. (23). NVivo 11 was used to facilitate data management and analysis. The researcher read and re-read transcripts to achieve familiarization which also led to the generation of initial codes. Further readings resulted in the identification of themes and sub-themes. This then led to the development of a working analytical framework. The identified codes were compared between the researchers (HAS, MB) and resulted in some modifications to the framework to include all viewpoints that led to them being grouped into clearly defined categories "Themes". The analytical framework was then applied to the entire data set, where data was indexed according to the codes, with new ones being duly noted. Finally, the data was charted into the framework matrix. This step involved charting summarized data for each code/theme from each transcript in NVivo 11.

Ethical consideration

Ethical approvals were obtained from each respective hospital site. Ethical approval for SQUH was obtained

from Sultan Qaboos University Medical Ethics Committee (SQU_EC/193/16). For the RH, ethical approval was obtained from the Ministry of Health (MoH/DGPS/CSR/45/2016). Ethical approval was also been obtained from the University of Nottingham's Medical School Ethics Committee (OVS 14112016).

Results

Participant demographics

Twenty women (10 from each infertility clinic

in the two selected hospitals) were successfully interviewed. The mean age of women was 28 years (range from 19-35 years). Most women were from the region of Muscat (n=7, 35%). Half of the them were in employment and the majority of them had a high school education or a higher educational degree (n=17, 85%). An average of 4 years (range 1-12 years) trying to conceive was reported by participants and the sample married for an average of 5 years (range 1-12 years, Table 2).

Table 2: The demographic characteristics of study participants (n=20)

Patient study ID	Age (Y)	Residence	Employment status	Educational level	Years of marriage (Y)	Years trying to conceive (Y)	Conceived before	No. of Times conceived	Years of fertility Treatment (Y)
SQUH1	22	Sumail	Yes	Primary	7	7	No	-	7
SQUH2	31	Mudhaibi	Yes	Bachelor	10	8	Yes	1	8
SQUH3	32	Wadi bani khalid	No	High school	12	12	Yes	1	12
SQUH4	22	Muscat	No	Bachelor	3	3	No	-	3
SQUH5	19	Nizwa	No	High school	1	1	No	-	1
SQUH6	27	Sumail	Yes	Bachelor	5	3	Yes	2	3
SQUH7	25	Fanja	No	Bachelor	2	2	No	-	1
SQUH8	30	Muscat	Yes	Secondary	4	3	No	-	3
SQUH9	28	Muscat	Yes	Bachelor	3	3	No	-	2
SQUH10	28	Rustaq	No	High school	5	5	Yes	2	5
RH1	32	Rustaq	Yes	High school	6	6	No	-	6
RH2	28	Nizwa	No	High school	4	4	Yes	1	3
RH3	27	Rustaq	No	High school	2	1	No	-	1
RH4	33	Muscat	Yes	High school	3	3	No	-	3
RH5	35	Musanah	No	High school	10	9	No	-	9
RH6	34	Muscat	Yes	Diploma	4	4	No	-	4
RH7	24	Rustaq	Yes	Diploma	4	3	No	-	3
RH8	30	Barka	No	Bachelor	3	3	No	-	3
RH9	25	Muscat	Yes	Bachelor	2	2	No	-	1
RH10	31	Muscat	No	Primary	10	10	No	-	8

Table 3: The emerged themes and sub-themes from participants' interviews (n=20)

Main theme	Sub-theme	Frequency of sub-theme
1. Cultural aspects around infertility	1.1 Social expectations and beliefs around child-bearing	16
	1.2 Social pressure and attitudes towards infertile women	17
2. The impact of infertility on participants' emotions	2.1 Emotions among participants living with infertility	20
	2.2 Long-term fears and concerns due to infertility	17
3. Effects of infertility on couples' relationships	3.1 Feelings of guilt among women towards their husbands	18
	3.2 Infertility as a threat to marriage stability	11
4. Self-management strategies for dealing with infertility	4.1 Positive self-perception of infertility through use of spirituality	13
	4.2 Coping mechanisms adopted by participants	20

Qualitative findings

Four core themes were identified each with corresponding sub-themes Table 3. Quotes are labeled with a participant code e.g. 21YRS_3INF, where the initial number denotes participant's age, and (3INF) indicates the number of years the participant had been experiencing infertility.

Theme 1: Cultural aspects around infertility

Social expectations and beliefs around child-bearing

Half of the participants admitted being blamed for the pregnancy delay by their relatives and relative in laws. Women expressed that culturally, pregnancy delay was always considered a woman's fault. Also, Participants reported a societal belief that women inherit their subfertility from their families, where some participants shared that with their relative in laws suggested that the problem must run in women's families. "Sometimes they talk about my family problems with pregnancy delay to conclude that it is a genetic thing..." (31yrs_INF10).

Women reported that community and cultural expectations was that pregnancy should follow immediately after marriage. It was reported that not being pregnant within a year of marriage was enough for a woman to be labelled infertile by the society. Participants also admitted that societal views do not recognize or acknowledge this problem, that men may be the reason for conception problems, and blaming a man would be considered shameful, "Yes, it is me who is being blamed... despite that I am much, much younger than my husband but he refuses to do any investigations to check. They always say: you are the one who is causing this problem even before I started the investigations" (19yrs_INF1).

Many participants shared that family members and their friends routinely referred to non-medical causes that could explain their infertility, and these were commonly held as societal beliefs. For example, women divulged others believed that couples might be envied by others or that someone had cast their 'evil eye' (curse) upon the couple, to prevent pregnancy. As such, participants stated that they were often pressurized to attend religious healers called "sheikhs" to revert the act of devil. Although many participants admitted that they did not believe in such courses of action, social pressures led them to engage in such activities, due to hearing of some success stories, "My sister told me about a woman who does rubbing for women who has the same as my problem who successfully got treated and carried a pregnancy, but I am not convinced about it..." (31yrs_INF10).

Social pressure and attitudes towards infertile women

Different forms of social pressure were encountered by women on a daily basis. Half of the women mentioned being constantly compared to fertile women, by their relative in laws and to other couples who had either got married around the same time or after them who conceived

or had children already "I am living with my parents in law and his brother married after us and got children and they are constantly comparing us to them" 30yrs_3INF. In addition, women reported that fellow women were not shy about asking newly married women constantly whether they are pregnant, after only a few months of marriage.

Some participants stated that women in the community had exposed women with pregnancy delay to embarrassing situations and harsh comments. A 32 years old woman who had been trying to conceive for 6 years described that, "Once I was leaving my neighbour's house when I passed by a group of my other neighbours who commented loudly "why are you not pregnant yet? Do you think you are still young?!" 32_INF6. Other comments made these women inferior to fertile women, where one participant stated that women did not trust her to babysit their children as she was considered to lack experience.

Many women noted that people around treated them as if they were less feminine to other fertile women. Participants described this in a form of being labelled as disabled women, infertile or women with a defect in their femininity, due to not carrying a pregnancy. In addition women also described how infertile women were viewed as evil by women in the society, where women avoided telling them about their pregnancy and tried to avoid letting them hold their children, as they might envy them and cause something bad to happen to them or to their children: "People think we might be over sensitive and evil towards pregnant women or those with kids...so they stop telling us things such as hiding their pregnancy around us or if a woman is carrying her baby, she will try to avoid us or avoid allowing us carry her baby" 33yrs_3INF

Theme 2: The impact of infertility on participants' emotions

Emotions among participants living with infertility

Participants reported feeling a mixture of emotions due to infertility. Loneliness was referred to commonly, as well as boredom which was attributed to not having children. As a result, these participants felt their homes were 'empty' and 'lifeless'. "I go out in the afternoon after work as I don't want to stay at home alone because it is so quiet and empty, so I like to go walking or spend time in my family house" 30 yrs. INF4. Furthermore, half of the participants had reported feelings of jealousy towards pregnant women. Some reported feelings of envy towards pregnant women, especially those who got pregnant despite getting married after them: "I know that most girls who are younger than me have children now and anyone who gets married will soon get pregnant within two months, I envy them" 28 yrs. INF3

Feelings of jealousy were also apparent towards women who already had children. Other women were more jealous when their husbands were interacting with other

children. In addition, more than half of the participants mentioned feelings of sorrow and sadness around their infertility. Feelings of sadness among these women normally stemmed from the external pressures they faced, most often from family and work colleagues questioning why they had not become pregnant or had children yet.” But I struggle emotionally in my workplace too much, from my colleagues’ constant talks about kids and questioning my pregnancy delay”. 27 yrs. INF5. Some participants described feeling emotionally drained and they often burst into tears when they were alone.

Long-term fears and concerns due to infertility

Many of the participants were open to share their fears and concerns from experiencing infertility. The desire to carry a successful pregnancy and experience motherhood was inherent among the sample. Many participants although were hopeful to conceive, expressed their concerns around never experiencing motherhood. Having such thoughts was terrifying to them as being mothers was an instinctive desire among women in general “The idea of having children is now becoming my life after waiting for so long and I wish I can have a child and I hear someone calling me “Mama” ...I’m afraid I’ll die before I get to experience this”31yrs_10INF. Some women expressed concerns about having difficulties conceiving with increasing age. These concerns were more common among those who had experienced infertility lasting 4 years and more. Several women were considering the longer-term implications of not bearing children, such as not having children to look after them during old age, which is typical in Omani culture,” Honestly, I think about my status when I am older...for example; my aunt is very old and a widow without children to look after her... and sometimes I say that I might be like her in the future” 35 yrs_INF10.

Theme 3: Effects of infertility on couples’ relationships Feelings of guilt among women towards their husbands

The majority of participants indicated their disappointment in not being able to fulfil their husband’s wish of having children, especially when they were the reason behind infertility (due to their PCOS). Many expressed their husband’s desire and care towards other children and how they felt guilty about being unable to grant them a child, “Now every time I have an appointment, I don’t tell him about it to avoid him accompanying me and not hear what they say in the clinic because it makes me feel more guilty about all this” 30 yrs. INF4.

Infertility as a threat to marriage stability

Despite many participants reporting feeling strongly supported by their husbands throughout their infertility journey, half of them expressed their worries about how difficulties and delays in conceiving could affect and threaten their marital status. The main concerns among these women related to thoughts about their husbands

remarrying to have children; Islam permits that men can marry up to four wives. “Yes, for sure I’m worried that my husband might marry another woman, the fear is always there” 24 yrs. INF4. Others were worried about getting divorced or for their husbands to no longer feel attached and affectionate towards them. Factors contributing to such tension included men being subjected to social pressures from their families, particularly to remarry if their wives were deemed to be taking too long to conceive. A few participants also revealed how the issue of pregnancy delay has already affected the stability of their marital life and this was more apparent among couples who had been trying to conceive for four years or more, “Yes it affected us so much...I can feel that we became less connected with each other because he is out of the house most of the day and there is nothing that connects him to me..”31 yrs_INF4.

Theme 4: Self-management strategies for dealing with infertility

Positive self-perception of infertility through use of spirituality

Women appeared to be using self-comforting techniques to accept, manage and cope with their infertility, which centred around religious and spiritual beliefs and seemed to lift their spirits and keep them motivated and positive about fertility treatment and the chances of success. Many participants seemed to be relying heavily on their faith in God and often referred to ‘God’s will’ as being important in reconciling their desire to be pregnant and being unsuccessful thus far, which seemed to be of comfort to them. Women reported getting closer to God gave them the strength to go through childlessness, with many sharing that they engaged in prayers, reciting verses from the holy Quran and asking for God’s forgiveness for any sins. Participants felt that engaging in these practices would help us to ensure that their prayers were answered, and that they are granted children.

Coping mechanisms adopted by participants

Women mentioned that they took up different activities, such as household activities, meeting up with family and friends, going out for a walk or watching television throughout the day, to distract themselves from the feelings of childlessness. Other adjustments participants reported included moving out of their in laws’ house and into their own home to self-isolation and avoiding to attend social gatherings like weddings, funerals and birthday parties to avoid the negative comments and questioning around their infertility. Half of the participants committed to eating healthily and engaging in physical activity, as many had been advised to lose weight by their HCPs, to increase their chances of conception. Women also shared that their ability to cope with infertility gets easier with time, and built resilience against societal and cultural pressures and expectations. “But all I can say is Alhamdulillah (thank God) I got used to it now and I get less affected by people words”. 34 yrs_INF4.

Discussion

Omani women with PCOS and infertility face tremendous amount of negative psychosocial pressure due to their childlessness which reflects the high social value placed on having a child after marriage in the Omani culture. Women are always blamed for infertility and it is shameful to attribute childlessness to men as it affects their masculine image in the society. Given the religious background of participants they reported holding on the belief of faith on god's will and destiny however women still go through intense emotions of sadness and sorrow due to their condition but also feelings of inferiority and guilt being the ones responsible of infertility in the relationship. Therefore, different strategies to cope with their childlessness were adopted including following a healthy lifestyle since majority are overweight or obese due to PCOS, avoiding social gatherings and moving out of their in-law's house where most of the harassments are coming from.

Existing literature on infertility among women from the developed world shows it has impacted upon women's emotional wellbeing and their identity including how they perceived themselves as women (24, 25). However, studies comprising women from the developing world report women experiencing mental and physical abuse, due to their infertility suggesting cultural differences exist (26, 27). In the developing world bearing children soon after marriage is a norm, which symbolizes a man's fertility and thus his masculinity (28). Our findings add to such literature and further highlights that women are exposed to cultural and societal pressures to conceive, particularly from in laws, with delays in conception routinely being attributed to women. Previous research from India and South Africa also reports that it was not uncommon for women to be questioned about why they had not conceived, which often led to public ridicule (29) and also a finding shared by our Omani participants. Social discrimination against infertile women by means of isolating these women during conversations about pregnancy and childbirth was also observed in this study. Infertile women were also considered untrustworthy in taking care of family children as they lacked the experience to do so which made them feel inferior to other women.

Moreover, the economic consequences of infertility were apparent in studies from the low-income countries of the developing world. Children are viewed as a source of income as child labor is common, and it is an additional source of income which these families are deprived of (30). In contrast, the value of having children in the Omani society is different to that perceived in the other developing countries. In Oman children are seen as a source of social security in older age rather than a financial source. This might be related to Oman being classified as a middle-income country where people are more secured financially compared to low resources countries. Women in this study revealed their fear not to have children to look after them in older age and thus become socially

abandoned, as it is common in the Omani culture for parents to live with their children when they become old. Nursing homes are not the norm in Oman and are rare in existence. In addition, religiously children are obligated to look after their parents at an older age and abandoning them is considered a sin.

Therefore, prevalent feelings of sadness, sorrow were reported and was seen to be debilitating. A recent case control study in Oman among women with PCOS using standardized questionnaire, showed them to be at a higher risk of suffering from stress, anxiety and depression compared to controls (31). In contrast, Other studies reported that depression and anxiety were still found to be common among women with infertility in different parts of the world due to their childless status regardless of their demographic characteristics or the experienced social pressure (32, 33).

Therefore, in order to minimize adverse psychological consequences, women in this study adopted different coping mechanisms to live with their infertility. Given the religious context of the region, results in this study have showed women using their faith in God and destiny to get the strength and support in accepting their pregnancy delay. Studies worldwide have showed women to be the most affected by their infertility and to adopt emotion-focused coping strategies such as crying, praying more and having faith in God. These spiritual and religious beliefs were commonly practiced among infertile women in different parts of the world (21, 34). The other reported coping mechanisms among participants in this study were similar to those reported worldwide among women with infertility who also adopted social adjustment mainly in the form of social isolation to avoid exposure to disturbing comments about their childlessness (35). Research has generally shown that women who get isolated socially and opt not to share their emotions, cope worse than those who share their feelings with others (36).

Furthermore, this study showed that majority of women adopted a healthy lifestyle through starting on a healthy diet and engaging in physical activity as a way to cope with their infertility. This might be a unique coping mechanism to women with infertility due to PCOS. These women struggle with being overweight. Attempts of these women to reduce their weight and therefore increase their chance to conceive might be the only way for them to feel having control over the situation and decreases their feelings of guilt being the ones responsible for pregnancy delay. Although the majority of women in this study were surprisingly strongly supported by their husbands despite being the reason behind infertility, this support seemed to fade away the longer the infertility persisted. The continuous routine, boredom of staying at home with no children and exposure to people's pressure had weakened the couple's relationship and threatened its continuity. The negative effect of infertility on marriage was common in

the developed world, where divorce was prevalent among married couples with infertility (36, 37). In comparison, studies in the developing world reported a more violent response from women's partners/husbands due to their childlessness (38) including domestic violence reported throughout Iran (39).

Since the experience of infertility is a phenomenon with both psychological and social dimensions, there was a need for it to be evaluated in the context of the Omani culture. In addition, the fertility clinics in this study get referrals from different cities in Oman, including from private clinics due to its advanced nature and this allowed to capture the experiences of a diverse sample of women.

This study has included only infertile women with PCOS being the cause of their infertility, thus they were the reason behind the pregnancy delay. Therefore, their psychosocial experience with infertility might be different to those with male factor infertility or to couples with mutual causes of infertility. Moreover, the experience of women who have stopped seeking fertility treatment for different reasons were not captured in this study and since the focus of this research was on infertility, the impacts of the other physical symptoms of the syndrome were not studied.

Conclusion

We conclude that the obtained data provided a better understanding on how Omani women with PCOS perceived the social pressure due to their inability to conceive, the impact of childlessness on them and their marital relation and the coping mechanisms adopted to overcome their infertility. It is therefore, recommended that fertility health care providers consider patient's emotional wellbeing during medical consultations and offer a standard level of emotional support to help these women psychologically during their medical treatment journey.

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Authors' Contributions

H.S.; Project development, patients' interviews, data analysis and manuscript writing. L.S.; Data analysis review and manuscript editing. J.G.; Data analysis and manuscript review. L.F.; Manuscript review and editing. M.B.; Project supervision, data analysis and manuscript editing. All authors read and approved the final manuscript.

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