

## The emotional-psychological consequences of infertility among infertile women seeking treatment: Results of a qualitative study

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### Abstract

**Background:** Infertility is a major life event that brings about social and psychological problems. The type and rate these problems in the context of socio-cultural of different geographical areas and sex of people is different.

**Objective:** The aim of this qualitative study was to explain the psychological consequences of infertility in Iranian infertile women seeking treatment.

**Materials and Methods:** This qualitative study was done using qualitative content analysis on 25 women affected by primary and secondary infertility with no surviving children in 2012. They were purposefully selected with maximum sample variation from a large Fertility Health Research Center in Tehran, Iran. Data were collected using 32 semi-structured interviews and analyzed by the conventional content analysis method.

**Results:** The findings of this study include four main themes: 1. Cognitive reactions of infertility (mental engagement; psychological turmoil). 2. Cognitive reactions to therapy process (psychological turmoil; being difficult to control in some situations; reduced self-esteem; feelings of failure). 3. Emotional-affective reactions of infertility (fear, anxiety and worry; loneliness and guilt; grief and depression; regret). 4. Emotional-affective reactions to therapy process (fear, anxiety and worry; fatigue and helplessness; grief and depression; hopelessness).

**Conclusion:** This study revealed that Iranian infertile women seeking treatment face several psychological-emotional problems with devastating effects on the mental health and well-being of the infertile individuals and couples, while the infertility is often treated as a biomedical issue in Iranian context with less attention on the mental-emotional, social and cultural aspects.

**Key words:** Infertility, Consequences, Psychological, Treatment- seeking, Qualitative study.

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## Introduction

Infertility is a life crisis with a wide range of socio-cultural, emotional, physical and financial problems (1, 2). More than 80 million people worldwide are infertile. Infertility rates vary among different countries, less than 5% to over 30% (3). In Iran, a widespread study was conducted in 2005 to determine the prevalence of infertility. The study showed that 24.9% of the couples had experienced primary infertility during their married life (4).

The evidence demonstrates that most infertile people on the globe live in developing countries and having children in these settings is often the only way for women to enhance their status in the community (5). Despite the

fact that 40% of infertility are male-related, 40% are female-related and 20% are related to both or to unknown causes, in some communities the childbearing inability is almost always attributed only to "woman" and that women are often blamed for infertility even if the cause of infertility does not relate to them (5, 6).

While the infertility is not a disease, it and its treatment can affect all aspects of people's lives, which can cause various psychological-emotional disorders or consequences including turmoil, frustration, depression, anxiety, hopelessness, guilt, and feelings of worthlessness in life (7-12). For instance, a quantitative study in Iran revealed that infertility treatment is amongst the most stressful factors for the infertile women (13).

The overall prevalence of psychological problems of the infertile couples is estimated to be 25-60%, which is caused by a complexity of factors such as gender, the cause and duration of infertility, treatment methods, and culture (2, 14, 15).

The review of the literature reveals that the infertility-related complexities and life experiences are highly influenced by the socio-cultural context in which the infertile person lives, so any comprehensive study on the subject with disregard to this context is futile (2, 16, 17). The cross-sectional quantitative studies are still common in dealing with the social and psychological consequences of infertility, regardless of their inadequacies in sorting out cause and effect (2). This study was designed and conducted qualitatively to examine the psycho-emotional consequences of infertility and its treatments.

## Materials and methods

To explain experiences of Iranian infertile women seeking treatment from psychological-emotional consequences of the infertility, Naturalism paradigm with qualitative research approach was taken (18). A type of qualitative content analysis (QCA) was drawn on to manage and analyze data gathered from the participants, women with primary and secondary infertility with no surviving children in 2012.

Qualitative content analysis is a suitable method for obtaining valid results as text data to produce knowledge, new ideas, facts, and practical guidelines for performance. This method is used for the subjective interpretation of text data content. The aim of this method is to classify and describe a phenomenon (19). Therefore, we use it in this study for deep interpretation of various data collected from experiences of infertile women seeking treatment regarding psychological consequences of infertility and its treatments. The study setting was the Vali-e-Asr Fertility Health Research Center in Tehran; where on average about 1500 infertile women from different parts of the country refer there for treating their infertility annually. All of the patients have to self-finance their infertility treatment expenses. This Center, as the government-funded center, subsidizes part of treatment expenses. The total cost for In vitro fertilization (IVF) and Intrauterine Insemination (IUI) treatments was roughly USD 1,250\$ and USD 100\$, respectively, at the time of data collection. The ethics committee of Shahid

Beheshti University of Medical Sciences confirmed conducting the study project.

The sampling procedure was purposeful sampling, which means selection of the individuals who are rich sources of information needed to examine the phenomenon under study (18). These individuals are selected with the help of clinical records, consultation with the medical team, and observation of the behavior and interactions of infertile women with medical team. Moreover purposeful sampling is based on a number of criteria. In this study the inclusion criteria are infertilities were only women-related, they should be diagnosed by a physician and specified clearly in clinical records; no chronic diseases or mental illnesses were involved; couples had no adopted children; and the women under treatment were willing to participate in the study.

Interviews continued until data saturation, which consisted of 23 participants. To ensure, two additional participants were also interviewed. At the beginning, the required explanations were given to the participants covering. The aim of the study, reasons for the selection of infertile women to investigate, their role in the study, benefits gained by their participation in the study, confidentiality of information, their right to participate or withdraw, how to contact the researcher, and an informed written consent was taken from the participants covering. Data were collected using intra method triangulation (18). In this method several ways were used to collect data, including: semi-structured interviews, observations, field notes and clients' records.

Five Open-ended questions were designed as an interview guide. Questions which are centered on purpose of research and were determined with the help of supervisors and colleagues then were surveyed and evaluated in three pilot interviews. Duration of the interviews was estimated between 60-90 minutes. Interviews began with the question "What was your first reaction when understand you have a fertility problem?" The next questions were asked according to participants responses. All interviews were conducted by the main researcher. During the interviews, attention was focused on the non-verbal behaviors of the participants. Number of the interviews was one or two times for each participant.

Overall, 32 interviews were conducted with 25 participants. After each interview, information was recorded with the consent of the participants, in the shortest possible time

after two to three times of listening. Simultaneously in process of data collection, the data analysis phase was performed (18). Covert or nonreactive observation of actions, reactions and dialogs of the infertile women in the various parts of the Infertility Center such as the reception waiting room, the admission, examination and sonography rooms, and examination room of diagnostic procedures were also recorded. The field notes were properly recorded and immediately analyzed in detail. Overall, the data collection and analysis procedures lasted from January to October 2012.

As aforementioned, the phase of data analysis was performed using the conventional content analysis as a type of QCA. In this method, the systematic classification processes are used to identify codes and themes within the content of the study (19). In this QCA, codes were extracted from the meaningful units of the participants' descriptions and classified according to similarities or dissimilarities, based on which the relevant themes were identified. For the rigor the data collection process the four criteria of Lincoln and Guba was used: including credibility, dependability, confirmability and transferability (18). In order to different methods were used, such as the diversity of participants, engagement with the participants and the research setting, clarifying the participants on the objectives of the study, data analysis of transcriptions immediately after the interview and feedback for the next interview. The data were verified, corrected and revised using the voices and reactions of the participants and observers. Research process was done from the beginning to the end under the supervision of supervisors and peer debriefing. Some auditory files, typed and coded interviews and all initial codes and categories were evaluated by peer debriefing. Some typed and coded interviews were examined by member check.

All collected and recorded data have been saved as computer files for reviewing and peer debriefing if needed. To examine the transferability of the study, data were made available to the several of infertile women who did not participate in the study, asking them to compare the results with their own experience (18).

## **Results**

A total of 25 women with a history of primary and secondary infertility with no

surviving children were interviewed. Women were 21-48 years old. One of them was illiterate and the other's education ranged from elementary to the Ph.D. degree. In terms of duration of marriage and duration of infertility treatment, they ranged from 3 to 22 years and 1-14 years, respectively. Two of them had more than one decade experience in seeking and doing infertility treatment. Some other relevant characteristics of the women are also described in table I. These characteristics of participants in study sample with the maximum sample variation can provide more help to the validity and transferability of findings to other similar groups and settings (18).

As infertility and its treatment process can both cause psychological-emotional consequences in the participants, these varieties of consequences were grouped to psychological-emotional consequences of the infertility and psychological-emotional consequences of treatment process in this study. In this view, main concepts obtained from the data were categorized into four main themes and their sub-categories (Table II). This scheme of separation in some instances led to sub-categories as psychosocial turmoil as seen in two themes; one related to the infertility and the other related to its treatment process.

### **Cognitive reactions of infertility**

This theme includes two sub-categories: mental engagement and psychological turmoil. According to participants' experiences, the topics such as possibility of remarriage of spouse, curiosity of the significant others about the infertility of the participant, and regret feelings the husband's in witnessing fertile couples were the causes of mental engagement of the participants. In addition, some pregnant women hiding their pregnancy from the participants also caused them to become mentally engaged. Also the participants who had hidden their infertility always had mental engagement that what would happen if the issue was disclosed. As one of the participants stated, "I am constantly thinking if people are aware of my problem what will happen" (Participant17).

Moreover, sometimes participants were upset by hearing about pregnancy or childbirth of a woman, talking of the husband and the kids and humiliating behaviors of some people. One of the participants expressed her feelings in this choked voice, "some pregnant women or those recently given birth touch my

head with their right hand, which really upsets me" (p4).

### **Cognitive reactions to the therapy process**

This theme includes the sub-categories as follows: psychological turmoil; being difficult to control in some situations; the reduced self-esteem and feelings of failure. Many participants were upset following the events that were generated in the treatment process such as hearing negative pregnancy test especially when they spend a lot of money, consuming drugs and passing treatment steps that in some procedures were invasive. The needs for surgery on the genitals or using a surrogacy or oocyte donation caused tremendous shock to them.

As one of the participants said, "When the doctor told me that I have to use a donated ovum, I was shocked" (p13). In such conditions, participants were losing control over their emotions and actions. A participant declared her feeling in this way: "I was so distracted while driving home that I had an accident and actually cried. I was frustrated and asked God "I'm really tried. What should I do?" (p6).

Frequent failures in remedying infertility in some participants and learning about the failure of other treatments at the Infertility Center which some participants experienced reduced their self-esteem. Women who become pregnant, which afterwards end in miscarriage, experience a sense of failure. As some of women said with tearful eyes, "So much medicine and treatment substantially reduced my self-confidence" (p12). Another participant stated "I was sure the fetus will stay and that I am becoming mother from the moment they implanted it, but finally I lost my child" (p16).

### **Emotional- affective reactions of infertility**

The third theme consists of the sub-categories of fear, anxiety and worry; loneliness and guilt; grief and depression and regret. According to the results, fear and anxiety from disclosure of infertility from persistence of absolute infertility happens for many participants. As one of the participants expressed, "I fear that I can never have a child particularly that my husband eternally loves and supports me. I constantly ask God, don't disappoint me in this way" (p19). Another participant said, "Although I told my husband before marriage that I have problems to become pregnant, but I'm afraid what happens in the future" (p7).

Turning age 30 as a restriction on fertility and the social pressure around on the husband of participants due to fertility problems were their main concern in the family. As narrated by one of the participants "I cannot stand the way people look at me and my husband. Needless to say that I fear my husband gets disrupted again. His feelings are really essential to me" (p14). Another participant said, "Since I got married very late. I'm concerned about not to respond to treatment" (p25).

There are feelings of loneliness and guilt from items that were reported by participants. As a participant expressed, "My home is silent from morning to night so that sometimes I am talking to myself in the fear of not becoming dumb" (p4). The participants who get emotional support from their families, especially from their husbands, have a feeling of guilt not being able to make their husband the father of a child. As one of participants stated, "I have tested my husband several times he is so gentle and never blames me as an infertile woman. This constantly causes my guilt consciousness as I think I am the source of his misery in this regard" (p16).

Most participants, however, experienced sadness one way or the other due to expressed worries by the family members, the bitter reactions of their community or being blamed by their husbands for the infertility. These issues were generally related to the duration of infertility and the longer the participants experienced infertility, the more they became depressed. As one of the participants stated, "12 years of infertility is a life time. Now I am completely depressed. I can bear no more" (p20). Another sub-theme was the theme of regret created in participants when they see a family embracing a child, conduct and observe pregnant women, small children and babies especially while they are being breastfed, or call "Mommy". A participant expressed her feelings in these words, "When I see a pregnant woman, I say to myself: God, when will I be wearing pregnant women's clothes?" (p23).

### **Emotional-affective reactions to the therapy process**

This theme includes four sub-categories of fear, anxiety and worry; fatigue and helplessness; grief and depression; and hopelessness. Fear of taking a pregnancy test result and fear of telling the husband the negative result in some participants, anxiety about how the therapy process proceeds and

concerns about the result of treatment are some of issues experienced by the participants. As a participant said, "I am worried if I do all of these and results turn out to be negative, what I should do" (p10).

The frequent use of hormonal treatments and non-medical interventions such as IUI and IVF and repeated failures was frustrating for some of the participants. Frequent and long trips from participants' hometowns to the infertility center as well as unexpected length of treatment cycles made some of them exhausted and hopeless, as one of the participants stated, "I am really tired after so many years, really exhausted" (p22).

Another participant said, "Sometimes I feel really frustrated, I like to commit suicide" (p5). Experience of such boring conditions has caused many participants to become grief-stricken, and depressed. A participant narrated her experience in this way, "Whenever I see that my test result is negative, I say to myself 'I wish I could become pregnant'. My heart is full of sorrow and pain" (p10). The observations done in the

field of research indicated that the participants were frequently surprised and concerned about costs of the treatments.

Some participants were asking the medical staff about where they could get loan or reduce costs, to which unfortunately they did not receive an encouraging answers. Some participants for providing costs stopped treatment. As one of the participants expressed, if the system is performed successfully I can apply IVF. I cannot do it as it is not affordable; I have nobody and no source to seek help" (p8). When participants with plenty of difficulties were able to provide for the cost of the treatment and started the process of treatment with hopes or dreams for the fertility, the prospects of defeat would become intolerable to them. Extreme hopelessness captured them when the fertility test after the treatment was positive but after a few weeks the pregnancy was interrupted. One of the women expressed her feeling by these words, "When a lot of enthusiasm results in failure, you become extremely hopeless and disenchanted" (p3).

**Table I.** The personal characteristics of the participants in this study

N. P <sup>a</sup>	Age	Education	Occupation	Duration of marriage	Type of infertility	Duration of infertility	Duration of treatment	Type of treatment
P1	21	High school diploma	Housewife	3 years	Secondary	2 years	2 years	M <sup>b</sup> + IUI <sup>c</sup>
P2	31	High school diploma	Housewife	7 years	Primary	6 years	6 years	M + IVF <sup>d</sup>
P3	31	Bachelor's degree	Employee	3 years	Secondary	2 years	2 years	M + IUI
P4	30	High school	Housewife	10 years	Secondary	7 years	6 years	M + IVF
P5	43	Primary school	Housewife	22 years	Primary	14 years	7 years	M + IVF
P6	33	PhD degree	Employee	10 years	Secondary	2 years	2 years	M + IVF
P7	25	Bachelor's degree	Employee	5 years	Primary	5 years	2 years	IVF
P8	35	Illiterate	Housewife	5 years	Primary	3 years	3 years	M
P9	39	Bachelor's degree	Employee	3 years	Primary	2 years	2 years	M+ IUI + IVF
P10	24	Middle school	Housewife	10 years	Primary	8 years	8 years	M+ IUI + IVF
P11	34	Primary school	Housewife	8 years	Primary	7 years	7 years	M + IVF
P12	27	High school	Housewife	7 years	Primary	6 years	6 years	M + IUI
P13	23	High school diploma	Housewife	2 years	Primary	1 years	1 years	IVF
P14	29	Middle school	Housewife	5 years	Primary	3 years	3 years	M + IUI
P15	36	Bachelor's degree	Employee	3 years	Primary	2 years	2 years	M + IVF
P16	30	High school	Housewife	7 years	Secondary	2.5 years	2.5 years	M + IVF
P17	26	Bachelor's degree	Employee	3 years	Primary	2 years	2 years	M + IUI
P18	28	Middle school	Housewife	3 years	Primary	2 years	1 years	M + IUI
P19	27	High school diploma	Housewife	4.5 years	Primary	2.5 years	2.5 years	M + IUI
P20	31	Middle school	Housewife	13 years	Primary	12 years	12 years	M + IUI
P21	37	High school diploma	Employee	13 years	Secondary	12 years	5 years	M + IUI
P22	35	Primary school	Housewife	15 years	Primary	14 years	14 years	M + IUI + IVF
P23	29	Master's degree	Employee	6 years	Secondary	4 years	4 years	M + IUI
P24	22	Middle school	Housewife	8 years	Primary	6 years	1 years	M + IUI
P25	48	Middle school	Retired	7 years	Primary	6 years	6 years	M + IVF

<sup>a</sup>N, P= Number of participants

<sup>b</sup>M= Medicinal

<sup>c</sup>IUI= Intrauterine Insemination

<sup>d</sup>IVF= In vitro fertilization

**Table II.** The main themes and sub- themes in this study

The main themes	Sub-themes
Cognitive reactions of infertility	Mental engagement; psychological turmoil
Cognitive reactions to therapy process	Psychological turmoil; being difficult to control in some situations; reduced self-esteem; feelings of failure
Emotional-affective reactions of infertility	Fear, anxiety and worry; loneliness and guilt; grief and depression; regret
Emotional-affective reactions to therapy process	Fear, anxiety and worry; fatigue and helplessness; grief and depression; hopelessness

## Discussion

Reproduction in the Eastern cultures is one of the highest values and when the childbearing seems impossible, probable psychological crisis sets in (20). This study was designed and conducted qualitatively to examine the psycho-emotional consequences of infertility and its treatments. Being consistent with the Noorbala *et al* study done in Iran, the present study showed that having children has a significant impact on the mental health of infertile couples, stabilizing women status within the family and community (5, 13). As infertility causes a woman's inability to achieve the desired social role, it is often associated with psychological distress (2).

On the other hand, the dramatic advances in the assisted reproductive technology have acted as a double-edged sword, itself causing mental, social, moral, financial, and legal concerns (21). Moreover, review of literature on the infertility consequences reveals that most studies did not conduct a separate inquiry and study of the psychological consequences of infertility and the consequences of its treatment (2). Therefore, the comparison of our study findings, with findings of the existing studies, is more or less difficult in some cases.

According to the existing studies, the use of therapies is one of the factors affecting the psychological problems of infertility (14, 15). As a systematic review by Gameiro *et al* revealed, in 21,453 infertile individuals from eight countries, the mental burden stemmed from the treatment has been one of the main reasons for the discontinuation of the infertility treatment (22). Fortunately, there are some studies in the literature that only discuss the psychological consequences of the treatment including IVF.

Participants in our study had experienced some psychological consequences due to both infertility and medical interventions like psychological turmoil, fear and anxiety and worry, grief and depression, but consequences like mental engagement, loneliness, guilt, and regret were only reported

as infertility consequences. The consequences like difficulty in self-control, reduced self-esteem, feelings of failure and helplessness, and hopelessness were experienced following treatment process. As Grill *et al* referred in their, the infertile women in this study have also experienced mental problems e.g. a sense of loss of personal control, grief, depression, anxiety and stress (2). Plus, the previous quantitative studies reported problems e.g. loss of self-esteem, anxiety, depression, guilt and grief (14, 15).

However, most studies have not separated the psychological consequences of infertility from its treatments or interventions. The findings of cognitive and emotional-affective reactions resulting from treatment process in this study are similar to the findings of Wischmann (2008). As he observed, many people being treated have more anxiety, depression and low self-esteem than the fertile peers (23).

What's more, in a study on infertile couples in an infertility treatment center, participants experienced emotions like deep grief, guilt, loneliness and fear of the future insecurity (20). However, many health care providers and mental health clinics still give little value to the negative psychological effects of infertility (12). These feelings were also experienced by participants in this study on the cognitive and emotional-affective reactions due to infertility. In a qualitative study, Khodakarami *et al* reported two sub-themes of guilt and unclear future (24). According to their study, person's guilt is rooted in her infertility which is consistent with our study. Another sub-theme is unclear future which resulted in frustration, worry and fear in infertile women. Similarly, one of the reasons for fear and worry in our study was unclear future. Fear of disclosure Infertility and unclear future of the present study was consistent with the results of the qualitative study by Shavazi *et al* (25).

Couples in the infertility therapy process are also encountered by some ethical issues such as oocyte donation and the surrogacy that can cause significant distress (12). Participants in this study were exposed to

such treatments with psychosocial turmoil. In a cross-sectional study of 585 couples who had been reported in women's using hormone injections, 53% reported discomfort on the treatment that failed, and 44% expressed anxiety while being treated. Two of the most common negative feelings were hopelessness and impatience. 49% of respondents reported they felt uncomfortable when they were around pregnant women or couples with children (26). Our participants also had experienced grief and hopelessness following repeated failures, anxiety during the treatment process and unclear result and the feeling of regret seeing pregnant women like some earlier studies in the literature (12, 20).

The stresses stem from the unaffordability of the infertility treatment costs, especially among people with no health insurance coverage were observed in this study. In addition, the infertility treatments are not still covered fully by the health insurance systems of the country, and this is why most Iranian participants were concerned about how to cover the costs. In this view, as Verhaak *et al* observed, there is reduction of depression and anxiety among women who had IVF even if they would lose a pregnancy chance (2).

As Dyer observed, despite of the differences in socio-cultural backgrounds in developing countries, many studies have shown that infertility consequences are often surprisingly similar there, but there is a significant difference between the experience of infertility in developing and developed countries (2, 10). Infertility in developing countries means a patient's body and a human identity has not completed that have directive consequence of the social and psychological, because fertility is so central to women's power (3). In developed societies voluntary childlessness is viewed as a more viable and legitimate option and women without children are often presumed to be voluntarily childfree in cultures in which there is no concept of voluntary childfree status, it is impossible to hide infertility (2). Distress of infertility, therefore, is likely to be greater in developing countries (27).

### **Conclusion**

This study showed that the infertility and its treatment process for Iranian infertile women is a source of psychological suffering with devastating effects on psychological well-being of infertile couples. The results also showed that one of the major causes of

psychological distress is the social pressure by community members. According to the results, while the medical discourse of infertility is dominant, its mental-emotional, socio-cultural and political aspects are still neglected in Iran.

As infertility is more common among people from the low social classes who do not have the ability to afford psychological counseling costs and social determinants play an important role in creating the psychological consequences of infertility, this study suggests that having professional trained social workers as complementary medical interventions in the infertility clinics is central to manage the issue of infertility in all aspects. This profession assistance not only meets the needs of infertile people but also the needs of the social system in which infertile people are living. In this view, social workers can support the rights and needs of infertile people as a means to development planning by policy-makers so that the infertility can be looked upon as a biopsychic social phenomenon.

### **Research limitations**

The researchers recognize the necessity of selecting their case studies from women with different socio-economic levels since it is an influential parameter on the complications following the treatment. However, since most advantaged infertile individuals use private infertility centers, and these centers denied researchers' request for interviews, the study does not include women from this group. The researchers tried to partially overcome this limitation with adding some cases to the study by picking women who use public clinics but they are from higher income families.

The recruited participants included women who had volunteered to participate in the study that, compared with non-volunteered infertile women, may have less psychological consequences.

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### Conflict of interest

The authors have no conflicts of interest.

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