



Original Article

# Infertile Couples' Needs after Unsuccessful Fertility Treatment: a Qualitative Study

Samira Ebrahimzadeh Zagami<sup>1</sup>, Robab Latifnejad Roudsari<sup>1,2\*</sup>, Roksana Janghorban<sup>3</sup>, Seyed Mojtaba Mousavi Bazaz<sup>4</sup>, Maliheh Amirian<sup>5</sup>, Helen T Allan<sup>6</sup>

<sup>1</sup>Nursing and Midwifery Care Research Center, Mashhad University of Medical Sciences, Mashhad, Iran

<sup>2</sup>Research Center for Patient Safety, Mashhad University of Medical Sciences, Mashhad, Iran

<sup>3</sup>Community Based Psychiatric Care Research Center, Shiraz University of Medical Sciences, Shiraz, Iran

<sup>4</sup>Department of Community Medicine, Faculty of Medicine, Mashhad University of Medical Sciences, Mashhad, Iran

<sup>5</sup>Department of Obstetrics and Gynecology, Faculty of Medicine, Mashhad University of Medical Sciences, Mashhad, Iran

<sup>6</sup>Department of Adult Child and Midwifery, School of Health and Education, Middlesex University, London, UK

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\*Corresponding Author:

PhD in Reproductive Health,

Email: rlatifnejad@yahoo.com

## ABSTRACT

**Introduction:** Infertility is a major medical issue. Investigations and treatment of infertility are the beginning of a complex, time-consuming and stressful process for couples that may fail well. The present study explored the needs of infertile couples following treatment failure with Assisted Reproductive Technologies (ARTs).

**Methods:** A descriptive qualitative study was conducted in an Iranian infertility center, in the Northeast of the country between April 2016 and June 2017. The researchers recruited 29 individuals including 9 couples, 9 women and two men with primary infertility through purposive sampling. The data were collected using semi-structured interviews and analyzed iteratively, using conventional content analysis with MAXQDA software.

**Results:** The main concepts obtained from the data were classified into one theme titled: "The need for support" and four main categories along with their subcategories, and included the need for psychological support, the need for more useful information, the need for social support and the need to access to supplementary services.

**Conclusion:** The findings show that following treatment failure, the infertile patients' expressed needs and preferences were not met. Identifying and meeting their needs may help the infertile couples to deal with ARTs failure and to reach a decision about future treatment.

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## Introduction

Infertility is a disease that is defined by a failure to achieve a clinical pregnancy after 12 months or more of regular and unprotected intercourse, (primary infertility) (World Health Organization 2018). Secondary infertility can occur when there is an inability to conceive after a previous successful birth.<sup>1</sup> In Iran, the prevalence of primary infertility is 21.1%.<sup>2</sup> Regardless of the type of infertility, women bear the burden of medical interventions related to the diagnosis and treatment of infertility, particularly Assisted Reproductive Technologies (ARTs) such as In Vitro Fertilization (IVF) treatment, cryo-preserved embryos, intra-cytoplasmic sperm injection (ICSI) and with the use of either non-donor or donor gametes.<sup>3,4</sup> ARTs are increasingly common methods of infertility treatment.<sup>5</sup> In Iran, approximately 29000 IUI and 35000 IVF and ICSI cycles were performed in 2011,<sup>6</sup> the rate of IUI is higher in Iran than it is in European countries, For many, the treatment is unsuccessful.<sup>4</sup> In the UK the live birth rate is 28% per treatment cycle when frozen embryos are used and 25% with fresh.<sup>7</sup> Nonetheless, after 12 cycles, cumulative live birth is expected to reach 85% in the long term if the treatment is not discontinued.<sup>8</sup> The success rate of ART in Iran is 23.94%.<sup>9</sup> Infertility treatment is associated with considerable distress and is often an emotional

rollercoaster typified by cycles of hope and despair.<sup>10</sup> Infertile couples incur significant emotional, financial and physical costs during the years of seeking infertility treatment, and their depression and anxiety increase after the failure of their treatment.<sup>11-14</sup> Moreover, unrealistic expectations for success may worsen the psychological distress following treatment failure.<sup>15</sup>

A systematic review showed that infertile women who experienced a failed cycle had high levels of stress, anxiety and depression, and low self-esteem and satisfaction with life.<sup>16</sup> Long-term negative psychological issues have been reported in infertile couples after an unsuccessful treatment.<sup>16</sup> Additionally, the psychological consequences of treatment failure can dramatically affect the individual's ability to seek and continue infertility treatments.<sup>17,18</sup> The termination of treatment following treatment failure is fairly high even in highly-motivated couples, being reported as 23% to 60%,<sup>19</sup> which may be due to the fear of failing again and the lack of knowledge.<sup>20</sup> There are few studies exploring the psychological and emotional needs of infertile couples after unsuccessful IVF. Need is defined as a measurable difference existing between the present and the desired status. Needs that exist can be identified.<sup>21</sup> Some quantitative studies on unsuccessful IVF treatment, have suggested that infertile couples' needs include educational and informational,<sup>22-24</sup> emotional<sup>25-27</sup> and

psychosocial<sup>28-31</sup> needs. Although quantitative studies are an efficient method for assessing the medical needs of a large number of patients, they have the disadvantage of restricting the patients' responses to a pre-made list of possible needs previously raised by the researchers.<sup>10</sup> Instead, qualitative approaches allow researchers to access the in-depth experiences of the participants and to see the world from their participants' perspectives.<sup>32</sup> In qualitative methods, in-depth explorations allow for the patients' needs to be uttered in their own words,<sup>10</sup> and their unique perspectives could reveal any neglected issues in relation to their needs. There have been few studies into Iranian couples' needs following infertility treatment failure, to the best of our knowledge.

A qualitative study in Iran which explored infertile couples' counselling needs during infertility treatment found that couples express a need for assistance and support in relation to psychological, sexual and marital needs as well as help with treatment, financial and legal matters.<sup>33</sup> In a British study, Machin interviewed 35 participants in three separate groups: clinic staff, patients attending the clinic and clinic directors. She showed a hierarchy of counseling needs in couples depending on the technique used and treatment involved. Couples having undergone donation procedures were more likely to express a need for counselling. Some couples felt that their needs were ignored when they needed the embryo donation.<sup>34</sup> In another study, infertile women said that they needed help in understanding their intense feelings and in deciding on the treatment options.<sup>35</sup> Gender has not been comprehensively studied in infertile couples, either; Sylvest et al., argued that not all the psychosocial and emotional needs of men are met in fertility clinics. In that study, men said that they needed empathy, understanding, kindness, recognition and acceptance from the staff. They believed they could have spoken about the psychosocial consequences of their infertility with the staff and received information before the treatment.<sup>36</sup> Given the lack of attention paid to the most stressful period of seeking infertility treatment, i.e. the period following the treatment failure,<sup>37</sup> when couples may need help to overcome the crisis of IVF failure, and decide whether to continue their treatment or not,<sup>38</sup> our study investigated infertile couples' needs after the treatment failure. Understanding and recognizing of these needs may assist the medical and nursing staff to understand and meet infertile couples' needs after ART treatment failure. Also, considering the lack of qualitative studies focusing on unsuccessful infertility treatment in the Iranian context and the lack of research emphasis on the needs of infertile couples following treatment failure in general, the present qualitative study was conducted to explain the perceived needs of the infertile Iranian couples following treatment failure with ART.

## Materials and methods

This study adopted a descriptive qualitative design. Qualitative Description (QD) is a useful qualitative method in medical and health research.<sup>9,39</sup> QD research questions aim to gain insight from key informants about

a poorly understood phenomenon.<sup>39</sup> This type of study is particularly appropriate in research projects aimed at gaining direct knowledge of the experiences of patients about a specific topic and can be used to provide useful data for clinical interventions and need assessments.<sup>9</sup> QD was used in this study in order to explore the needs of infertile couples after failed treatment with ARTs in their own words.

This study was conducted in an Iranian infertility Center, in the northeast of the country which admits infertile patients from all cities located in the east of Iran. Maximum variation sampling was conducted in terms of age, education, employment, duration of marriage, cause and factor of infertility, frequency of treatment, type of treatment and frequency of treatment failure. The inclusion criteria included Iranian couples with primary infertility undergoing treatment with ART with at least one treatment failure using ART, who were willing to participate in the study. The exclusion criteria were an unwillingness to conduct an interview, couples with secondary infertility, or who had an adopted child. Although couples were approached to participate in the study, not all couples participated together. This issue has been seen in other qualitative studies and is discussed as a limitation.<sup>40</sup> The researcher introduced herself to couples who had undergone previous unsuccessful treatment and now they had come for further treatment in the infertility center. The researcher verbally explained the purpose of the study, the type of questions and duration of the interview and answered any questions that came up. If they were willing to participate in the interview, the couples signed consent forms and the timing and place of the interview was arranged for the convenience of the couples.

This study was conducted with 29 participants: nine couples and another nine women and two men, (18 women and 11 men) selected through purposive sampling from the infertile couples attending the Milad Infertility center from April 2016 to June 2017. The data were collected through semi-structured interviews, conducted according to the participants' preferences either in their homes, workplace or the medical center.

The couples were interviewed together or individually. First, the interview was conducted with nine couples (18 participates) as together, because both were involved in the treatment and unsuccessful treatment. The interview was conducted with another 11 participants (9 women and 2 men) as individuals, in case one of the partners did not want to talk in the presence of her/ his spouse. In both interviews, the questions were asked about how they face the treatment failure, such as "Could you please describe your experiences after the unsuccessful infertility treatment?", "Have you faced or are you still facing problems following unsuccessful infertility treatment? In what ways?" "What were your needs and expectations from the infertility centers after unsuccessful treatment? Prompts were used to expand on the couples' answers, including "Could you please elaborate on that?" and "Could you be more specific?" The main emphasis of the interviews was on the needs of the couples after the treatment failure. The interviews then continued with the

question of "What are your expectations from the medical team and infertility treatment center after their treatment failure ", and based on the answers, further questions were asked if necessary. The interviews ended with the question of "Is there anything else you would like to add?" Each interview lasted between 40 and 95 minutes.

They were recorded and were transcribed verbatim at the earliest opportunity. All the non-verbal expressions, such as silence, laughter and crying, were added to the transcriptions. The transcribed interviews were reviewed a second time by the authors. The data were entered into MAXQDA-10. The texts were analyzed, using qualitative content analysis.<sup>41</sup> the interviews were analyzed in four stages. Stage 1, the interviews were read several times to obtain an idea of their content and to gain an insight and the whole idea through exploring of both latent and manifest content. Stage 2, the texts of each interview transcript were divided into meaning units defined as words, sentences and paragraphs within the text, where the content of different texts were related to each other and to the study objective. Stage 3, the meaning units were condensed and labeled with codes, and stage 4, the codes were compared in terms of similarities and differences, and the similar codes were placed in the initial categories. As the analysis progressed, the initial categories were developed and subcategories were formed.

The main categories then emerged from the integration of similar subcategories. The analysis of the data led to the extraction of 166 codes, 14 subcategories and four main categories. A maximum diversity of the participants with respect to their ART treatment protocols was achieved to enhance the credibility and acceptability of the data. In addition, prolonged engagement with the participants and the study setting, ongoing assessment of the data, transcription and analysis of the data immediately after the interviews and using participants' feedback for the next interview were used to further enhance the credibility and trustworthiness. Moreover, the condensed meaning units, codes and categories were confirmed by a number of the participants and by an external checker<sup>42</sup>, who were experienced qualitative researchers. The present study was approved by the local ethics committee of Mashhad University of Medical Sciences, Mashhad, Iran (Code: IR.MUMS.REC.1395.120).

## Results

The infertility causes in this study were male factor (abnormal sperm production or function), female factor (ovulation disorders, fallopian tube damage or blockage, endometriosis), male and female factor (mixed), and unexplained. The age range of the participants was 21-46 years. The range of infertility duration varied from 10 months to 18 years. Their education level varied from primary school to master's degree (Table 1). The participants received infertility treatment through IUI, IVF, ICSI and donated eggs in several centers, including private and public centers across Iran. The treatments

varied from one IUI cycle to five IVF cycles. IVF was performed in two of the couples with donated eggs.

Data analysis revealed one theme titled: "The need for support" and four categories regarding the needs of infertile couples, following treatment failure with Assisted Reproductive Technologies including *the need for psychological support, the need for more useful information, the need for comprehensive support and the need to access to supplementary services* (Table 2).

### The need for psychological support

The desire for counseling was one of the needs stated by the infertile couples. Counseling by a third party after the treatment failure may be helpful. Given that treatment failure affects both men and women and couples recall it as the worst stage of their treatment, the participants expressed their need for counseling. *"I think the most frequent, and the worst stage that everyone goes through is exactly where their IUI or IVF fails. I think that they need at least a telephone counseling at this stage"* (P 28, woman, 8 years of infertility, unexplained).

Men felt that their wives needed this talk more than they did. They acknowledged that, although the news of the treatment failure was upsetting for them as well, they tried to console their wives first and foremost, since it was more of an emotional issue for them. Nonetheless, their consolation sometimes had the reverse results and caused a misunderstanding in the women since men did not often know how to console their wives. *"Following the negative pregnancy test results, I tried to comfort her... we don't exactly know how to and have not been trained for it; ... a wrong word makes it all worse. ... and as soon as you say that it doesn't matter, they take it the wrong way, and think that it is not important to you, or that you might marry another woman and get her pregnant and that is why it is not important to you."*

*This is the kind of thing that comes to their mind, to women's mind.*"(In Iranian culture, men can have more than one wife) (P 14, man, 3 years of infertility, mixed). Some men argued that only women need counseling after the treatment failure due to their complex mental status while men are not touched by these problems. *"Men are more resilient and patient, and I think bearing infertility is much harder on women."* (P 12, man, 3 years of infertility, female factor). However one man likened the experience of the treatment failure to an earthquake and said that coping with this experience is like coping with earthquake and requires group counseling. *"If only there was a special care center to which to take these women after their operation, plus a counselor and a doctor for their anxiety. You see, after an earthquake, they send a counseling group in to lower people's stress"* (P 29, man, 8 years of infertility, unexplained). Interestingly, even though men stated that they believed women needed more support than they did themselves, infertile women declared *their need for the spouse's psychological support*. The majority of the women regarded their spouses' psychological support after the treatment failure as the reason for their relative psychological recovery.

**Table 1.** Individual features of participants

No	Gender	Age	Education	Job	Residential place	Duration of infertility	Cause of infertility	No. of interviews	Interview duration
1	Female	46	Master degree	Educator	Mashhad	2 years	Mixed	2	90 min
2	Female	43	Bachelor	Midwife	Mashhad	1 years	Mixed	1	40 min
3	Female	41	Elementary	Clothing retailer	Mashhad	16 years	Mixed	1	45 min
4	Female	28	diploma	Housewife	Birjand	5 years	Mixed	1	60 min
5	Female	37	diploma	Housewife	Mashhad	12 years	Mixed	1	40 min
6	Male	43	Bachelor	Manager	Mashhad	4 years	Mixed	1	40 min
7	Female	31	Bachelor	Accountant	Yazd	5 years	Female factor	1	75 min
8	Male	32	diploma	Employee	Mashhad	3 years	Male factor	1	45 min
9	Female	29	Associate Degree	Housewife	Mashhad	3 years	Male factor	1	50 min
10	Female	33	Bachelor	kindergarten trainer	Tehran	4.5 years	Male factor	1	85 min
11	Female	24	Elementary	Housewife	Mashhad	3 years	Female factor	1	56 min
12	Male	27	Elementary	Free job	Mashhad	3 years	Female factor	1	60 min
13	Female	30	High School	Housewife	Sabzevar	9 years	Unexplained	1	45 min
14	Male	46	Master student	Free job	Mashhad	4 years	Mixed	1	85 min
15	Female	33	Associate Degree	Accountant	Shirvan	2 years	Male factor	1	45 min
16	Male	28	diploma	Housewife	Shirvan	2 years	Male factor	1	50 min
17	Female	30	High School	Seller	Torbat	3 years	Unexplained	1	40 min
18	Female	21	diploma	Housewife	Torbat	3 years	Unexplained	1	40 min
19	Female	34	Bachelor	Housewife	Mashhad	5 years	Female factor	1	75 min
20	Male	35	Bachelor	Manager	Mashhad	5 years	Female factor	1	75 min
21	Male	35	High school	Worker	Neyshabour	10 months	Unexplained	1	40 min
22	Female	32	Elementary	Housewife	Quchan	11 years	Male factor	1	45 min
23	Male	44	Elementary	Painter	Bardaskan	18 years	Female factor	1	40 min
24	Female	36	Elementary	Housewife	Bardaskan	18 years	Female factor	1	45 min
25	Female	35	Elementary	Farmer	Kalat	6 years	Male factor	1	40 min
26	Female	32	Master degree	Teacher	Mashhad	4 years	Unexplained	1	45 min
27	Male	33	Bachelor student	Employee	Mashhad	4 years	Unexplained	1	55 min
28	Female	28	diploma	Housewife	Birjand	8 years	Unexplained	1	40 min
29	Male	35	Master degree	Teacher	Birjand	8 years	Unexplained	1	95 min

**Table 2.** Emerged categories and subcategories

Subcategories	Categories	Theme
	The need for psychological support	The need for support
Desire for counseling		
The need for the spouse's psychological support		
The need for empathy		
The need for stress management		
	The need for more useful information	
Unrealistic expectations due to the lack of information		
Informational needs		
	The need for comprehensive support	
Insufficient financial support		
Lack of support from charities and NGOs		
Non-effective participation of spouse in treatment		
Poor accountability of services		
	The need to access to supplementary services	
Asking for integration of infertility services		
Requesting traditional medical counseling		
Calling for nutrition counseling		

"My husband looked after me and supported me a lot, and this made me feel better" (P 7, woman, 5 years of infertility, female factor). Some of the participants were upset about the lack of support on the part of their spouses after the treatment failure and evaluated their husband's treatment of his wife within the family as disappointing. "My husband didn't even come home He repeatedly said, in front of everyone, that he wanted one too, that he would also like to hold and cuddle a child of his own " (P 13, woman, 9 years of infertility, unexplained). The need for empathy was another need expressed by the participants. Some of

the participants complained about the poor treatment on the part of some of the health care personnel. In addition to the psychological support, they needed appropriate humane treatment on the part of the personnel. "When I made a call to the center to ask why this had happened to me (negative infertility test), I mentioned that It was a long-distance call, they ranted, 'We can't be doctors over the phone! Visit in three months!', and cut me off abruptly. They were so cruel" (P 4, woman, 5 years of infertility, mixed). Infertile couples said that they need stress management after an unsuccessful treatment. The majority of the participants

said that they were more stressed out after yet another treatment failure. *"I'm not generally a stressful person, but I was surely more stressed out after the second failure"* (P 1, woman, 2 years of infertility, mixed). Some participants argued that there is a need for stress management training even during the treatment, which should be provided by the personnel. They considered stress as the cause of the treatment failure and noted the importance of stress management training by medical centers. *"I think, to get the desired results, the patient might need many things. The stress the patient has makes everything super worse. They should perhaps inject stress reduction, especially into women. We generally had nothing of the sort, no information and no one to talk to."* (P 20, man, 5 years of infertility, female factor).

### The need for more useful information

Infertile couples had unrealistic expectations due to lack of information. The majority of the infertile patients had no knowledge of the process of the treatment and the success rate of ARTs, which had led to unrealistic expectations of the infertility treatment and dissatisfaction following treatment failure. After their treatment failure, especially after the first one, they acknowledged that they had believed the success rate of the treatment to be 100%. They had found out about the actual success rate of ARTs through a web research after their treatment failure. Meanwhile, they wished that they had received this information from the medical team before undergoing the treatment.

*"They should provide us with information. I was very upset the first time, because I thought that starting the treatment meant pregnancy for sure. No one had told me that the probability of pregnancy with IVF was only a few percent,"* (P 7, woman, 5 years of infertility, female factor).

Informational needs were one of the main needs that were mentioned by the couples. The majority of the participants required information about the causes of infertility, various infertility treatments and treatment plans following the treatment failure, and revealed that they had not been given any information at these centers.

*"Well, information and training should be fully provided. For instance, they should explain what IVF is! What is the embryo? Where is it formed? What are these injections for?"* (P 10, woman, 4.5 years of infertility, male factor).

Some of the participants also stated that they had not received adequate information about the care needed to be given during the treatment and were not well informed about their medication administration. Others said that they had gathered information by themselves over the internet after their previous treatment failure. *"My husband went on the internet and found out that we should abstain. No one had told me about this"* (P 19, woman, 5 years of infertility, female factor).

### The need for comprehensive support

Insufficient financial support was another need-. All the participants reported financial issues as their number-one problem. Some explained that they had to sell their house, car, gold, jewelry and property to meet the costs of their treatment while others financed their treatment by borrowing money from others or taking loans, and their

main concern after the treatment failure was how to finance the continuation of their treatment. *"My worry right now is that now that I've come here again I have to pay money. It is all very hard. There is no place to go to and get help"* (P 25, woman, 6 years of infertility, male factor).

Most participants considered their insurance coverage inadequate. *"We have health insurance, but these two IVFs came to 7 million Tomans. They should increase the insurance coverage, you know"* (P 10, woman, 4.5 years of infertility, male factor).

The participants complained from the lack of support offered by charities and non-governmental organizations (NGOs). They referred to the lack of financial support from NGOs and the absence of organizations supporting infertile couples. The participants commonly proposed certain possible strategies for meeting their financial needs, which included help from the charities and NGOs.

*"The best way is through charity associations that we do not have for infertile patients,"* (P 29, man, 8 years of infertility, unexplained). NGOs can also play a role in supporting cancer patients. One participant argued that similar supportive institutions should serve infertile patients and said: *"NGOs are very good if there are for us, since many patients complain that there is no place to support them. Just like there are centers for cancer patients, there should be centers for infertile couples as well"* (P14, man, 4 years of infertility, mixed).

Infertile women were dissatisfied with non-effective participation of their spouses in the treatment and felt they had to be more serious. Some of the participants discussed their spouse's opposition to the continuation of the treatment after its failure, and this opposition was because of the high costs, distrust in the outcomes and having met people who had also had treatment failures. A female participant explained that such a behavior by her husband disheartened her and made her disappointed about seeking treatment: *"My husband tells me not to go, because I won't get what I want. He says I'll lose a lot of money for it and I'll lose my spirits as well."* (P 5, woman, 12 years of infertility, Mixed). Poor accountability of the services was another issue that the participants referred to. They discussed poor responsiveness in various dimensions of the system, including poor responsiveness toward the couples' questions and their confusion following the treatment failure. A male participant likened the center to a trade center where service is provided only at a trading level.

*"One of the problems here is that there is no one to explain the tests and the possibilities they offer. They should know which people have come here several times and done the IUI or IVF and have failed and should let them know what they need to do now. Also, there should be a follow-up before, during and after IVF. As I said, it's like a shop here, you go in and buy what you need and that is that"* (P 6, man, 4 years of infertility, mixed).

Since some participants had to travel for their treatment, one of their main problems was finding a place to stay in and the accommodation. Some stayed with their relatives, and those who had no friends or relatives in the city or did not want them to know about their problem had to incur accommodation costs in addition to the treatment costs. They wished for having a

short-stay guesthouse in the vicinity of the center. "We are told that we have to stay in a guesthouse, for like. They should have some places for those who come from other cities." (P 14, man, 4 years of infertility, mixed).

### The need to access to supplementary services

Most of the participants asked for the integration of infertility services. They wanted all the stages of the treatment to be performed in the same fertility center, including the tests and the preparation of medications. The patients' satisfaction with the centers that provided all these services in a single unit was reportedly higher than that observed in the other centers. Since some patients come from other cities and do not know their way around the city, they experience problems in some stages of the treatment which are performed outside the center. "The first time we came, we had to wait until 11.30-12. Then they sent us to the Hospital laboratory. How could we made it in such short time? By the time that we got back, the doctors had gone. We were told to come back the next day. So we had to make another appointment to see the doctor the next day. And this is a specialty center, and it would be better if all tests to be done right here" (P 29, man, 8 years of infertility, unexplained). Some participants had problems with the appointment scheduling system, including the lack of internet access in some areas and the need for presenting early in the morning to make an appointment. "We struggle a lot at getting an appointment. They give out the appointments online and we live far away from an internet café and don't have access to a computer." (P 12, man, 3 years of infertility, female factor). Some participants requested traditional medical counseling. Following the treatment failure, they wanted to use traditional medical counseling for receiving traditional treatments such as herbal medicine, acupuncture and other such treatments and wished to use this kind of medicine at the same time. They had seen good results in their peers who had used traditional medicine alongside ARTs. "There should be at least one attending traditional medicine counselor in the center" (P 29, man, 8 years of infertility, unexplained).

Some participants called for nutrition counseling. They called for nutrition counseling during the treatment process. Some said that they searched the internet for nutritional information. "I found this on the internet; what to eat and what not to eat to help get pregnant. But they tell us nothing about these issues at the center, although they should" (P 20, man, 5 years of infertility, female factor). "They never said this to us, what to eat and what not to eat before egg collection or between collections and transfer" (P 19, woman, 5 years of infertility, female factor).

### Discussion

The present qualitative study was conducted to explain the perceived needs of infertile Iranian couples following the treatment failure with ARTs. The participants expressed their need for psychological support, the need for more useful information, the need for comprehensive support and the need to access to supplementary services.

Many of the participants needed counseling, respect, stress management and psychological support from their

spouses for stress reduction, especially after the treatment failure. Read et al., reported that infertile couples have many needs for services and psychological support to overcome infertility-related distress. These services can be in the form of couple counseling or easily-comprehensible written material on the emotional and physical outcomes of the infertility treatment,<sup>10</sup> which agrees with the present findings. However this study also confirms the gendered nature of the reactions to IVF failure as more women than men expressed a need for support while at the same time, men located distress after IVF failure in their wives. According to a study conducted by Unsal and Karaca, the psychological problems faced by infertile women include negative self-concept and psychological symptoms. Although both genders are emotionally affected by infertility, women experience or display greater stress and pressure and are more strongly affected by anxiety and depression, so much so that the psychological pain of infertility has been likened to the pain caused by life-threatening diseases such as cancer and coronary artery failure.<sup>43</sup>

Psychological counseling that assesses infertile patients' psychological problems and stress can lead to a healthy treatment process.<sup>43</sup> Providing counseling to infertile people should be concerned with support, consultation, guidance and clarification of life purposes.<sup>44</sup> Moreover, many infertile patients acknowledge their need for counseling but do not actively seek it.<sup>45</sup> In some studies, infertile women argued that they did not need counseling and psychological and emotional support from counselors.<sup>44</sup> In the present study, some of the women who enjoyed their husband's and family's emotional support said that they did not require psychological counseling, even though they experienced severe stress and disappointment after their treatment failure. Some of the men argued that they did not need psychological counseling but their wives did, as women had greater emotional needs. The possible reason may be that men consider themselves stronger than women, and believe that women are psychologically more vulnerable. In addition, women feel guilty after an unsuccessful treatment.

On the other hand, women are involved in the treatment more deeply and go through all the intricacies of the treatment. This finding is congruent with what Sylvest et al., found in their study. It may also be that men were unable to openly describe their need for counselling due to cultural constraints. Furthermore, the patriarchal culture of the Iranian society shifts the blame onto women, however, at the same time, by shifting it away from men, it ignores their stress and emotional reactions to IVF failure. Nevertheless, it is necessary for the multidisciplinary team including doctors, midwives, nurses, psychologists and counselors to provide psychosocial support for the infertile couples and consider assessing the mental health of the infertile couples on different occasions and separately over the course of their treatment, and not just when visiting a new patient, since such consideration would also help to prevent complications and offer interventional strategies.<sup>11,46</sup> Other studies in relation to the psychological support of the infertile couples have found

that offering counseling services to these couples could help them to effectively manage their stress<sup>47</sup> and to adopt appropriate coping strategies<sup>48</sup> and to achieve to a higher level of marital satisfaction, as a result.<sup>49</sup> In the present study, infertile couples had a greater need for information about the causes of infertility, different ARTs, their success rate and also the care required during the treatment process after experiencing a treatment failure. In a cross-sectional study, Bennett et al., showed that 87% of the infertile women asked for more information on infertility. The patients' knowledge about the causes and treatment of infertility was reported as very poor in that study.<sup>24</sup> Two qualitative studies on infertility conducted in developing countries showed that the biological process of reproduction is often poorly understood by infertile patients.<sup>50,51</sup> Infertile patients wish to hide their infertility problems from their social circles in order to avoid the negative reactions of relatives and friends and their many questions. As a result, they need information at each complex stage of infertility treatment. The need for information about infertility leads infertile patients to searching the web. Satir et al., showed that most infertile patients use the patients internet to find information about ARTs and the causes of infertility.<sup>23</sup> Taghipour et al., argued that, according to the participating women, the weaknesses in professional communication and services include the medical personnel's weaknesses in providing information, their tendency to spend little time with infertile couples, their non-responsiveness toward the couples' needs and the semi-dictatorship in their relationship with the patients.<sup>52</sup> It is thus vital for doctors to have greater patience when dealing with their patients, try to understand them and explain the causes of infertility and the right treatments to them.<sup>53</sup> Another need the infertile patients referred to was comprehensive support, highlighting insufficient financial support as one of their main problems after the treatment failure. Given the limited resources in developing countries and the heavy costs of infertility treatment, these medical costs are not covered by supportive organizations such as insurance companies.<sup>52</sup>

All the participants complained about the heavy costs of the treatment and the inadequate insurance coverage for them and proposed solutions such as better insurance coverage, getting assistance from charities and NGOs and bank loans.<sup>20</sup> Although the number of NGOs has increased since 1990, their work is new in Iran. The majority of NGOs have several roles and there is little cooperation between NGO and local and international organizations in Iran.<sup>54</sup> In the present study, some participants argued that the ineffective participation of their spouse disrupts their treatment and creates family conflicts. Both women and men stated that men should be more involved in the process of treatment after the experience of the treatment failure. Sylves et al., stated that men wanted face-to-face conversations and verbal information, dialogue and an opportunity to ask questions.<sup>36</sup> This study confirms a gender gap in the expressed needs in infertile men and women. Nutrition counseling was another need discussed by the participants that was not provided for all the patients in the infertility centers; often, this counseling was only

provided to the obese infertile women, who were encouraged to lose weight. Meanwhile, some participants considered nutrition counseling necessary for all infertile patients.<sup>55</sup> A systematic review study showed that a healthy nutrition regimen improves at least one of the criteria of sperm quality, and high-fat foods and sweets reduce the sperm quality.<sup>56</sup> Some participants argued that they needed traditional medicine alongside ARTs.

Alfred et al., stated that some women believe traditional medicine might be helpful as part of the infertility treatment.<sup>57</sup> Various services should therefore be provided to meet the patients' many needs.<sup>10</sup> Strengths and limitations given that infertility is more common in lower socioeconomic classes,<sup>58</sup> and given that the researchers in this study were not allowed to conduct a study in private infertility clinics, the majority of the interviews in this study were conducted in public infertility centers, which are visited by low-income infertile patients, and this issue constitutes a limitation for this study. Nonetheless, a few of those attending these public centers had a previous history of seeking infertility treatment in private centers. One of the limitations of the study was that the needs of infertile couples have not been elaborated on according to either male or female infertility factor. Moreover, the majority of the participants (except for two) were patients who had visited after one or several treatment failures and might have had different psychological experiences and complications compared to those who had discontinued their treatments. The strengths of this study are that the interviews were held with a diverse range of participants in terms of age, education, occupation, duration and causes of infertility and ART used in the Iranian social context. This study has explored Iranian couples' experiences with specific cultural and religious perspectives. Most Iranians are Shi'a Muslim, and their most important coping strategy in dealing with critical situations such as unsuccessful treatment, is trust in God and praying.<sup>46</sup> On the other hand, in the Iranian society, childbearing is very important, so that the intention of many couples of marriage is childbearing.<sup>59</sup> Also this study explored men's as well as women's experiences in the patriarchal culture of Iranian society in order to highlight the gender issues influencing the experience of infertile couples confronting treatment failure. It seems that this study could also reflect the experiences of unsuccessful infertility treatment in other countries with a similar socio-cultural context so that it might enhance the awareness of health professionals in the region regarding the world of infertile couples confronting a treatment failure. In this study, both infertile men and infertile women stated their own and their spouses' needs after an unsuccessful treatment. The findings also suggest the need to do further studies to explore infertile couples' needs considering particular aspects of infertility such as the duration and causes of infertility as well as the issues of male or female factor.

## Conclusion

The present study provided an in-depth perspective on the needs of infertile couples following a treatment

failure and can be used as the basis for future planning for meeting these needs. The capacities and barriers of treatment centers for meeting infertile couples' needs and expectations should be further addressed.

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### Ethical issues

None to be declared.

### Conflict of interest

The authors declare no conflict of interest in this study.

### References

1. World Health Organization. Infertility definitions and terminology [Internet]. 2018 [Cited 2018 25 Feb]. Available from: <http://www.who.int/reproductivehealth/topics/infertility/definitions/en/>.
2. Rostamidovom M, Tehrani FR, Abedini M, Amirshakeri G, Mehrabi Y. Prevalence of primary and secondary infertility among 18-49 years old Iranian women: a population-based study in four selected provinces. *Hakim Research Journal* 2014; 16 (4): 8. (Persian)
3. Obeidat HM, Hamlan AM, Callister LC. Missing infertility. *Advances in Psychiatry* 2014; 7. doi: 10.1155/2014/241075.
4. Wirtberg I, Möller A, Hogström L, Tronstad SE, Lalos A. Life 20 years after unsuccessful infertility treatment. *Human Reproduction* 2007; 22 (2): 598-604. doi: 10.1093/humrep/del401.
5. Segev J, Van den Akker O. A review of psychosocial and family functioning following assisted reproductive treatment. *Clinical Effectiveness in Nursing* 2006; 9 (2): 162-70. doi: 10.1016/j.cein.2006.08.002.
6. Abedini M, Ghaheri A, Omani Samani R. Assisted reproductive technology in Iran: the first national report on centers, 2011. *Int J Fertil Steril* 2016; 10 (3): 283-9. doi: 10.22074/ijfs.2016.5044.
7. Fertility treatment 2014–2016 Trends and figures: Human Fertilisation and Embryology Authority; [Internet]. 2018 [Cited 2018 6 March]. Available from: [www.hfea.gov.uk](http://www.hfea.gov.uk).
8. Baird DT, Bhattacharya S, Devroey P, Diedrich K, Evers JL, Fauser BC, et al. Failures (with some successes) of assisted reproduction and gamete donation programs. *Hum Reprod Update* 2013; 19 (4): 354-365. doi: 10.1093/humupd/dmt007.
9. Neergaard MA, Olesen F, Andersen RS, Sondergaard J. Qualitative description - the poor cousin of health research? *BMC Med Res Methodol* 2009; 9 (1): 52. doi: 10.1186/1471-2288-9-52.
10. Read SC, Carrier M-E, Boucher M-E, Whitley R, Bond S, Zelkowitz P. Psychosocial services for couples in infertility treatment: What do couples really want? *Patient Education and Counseling* 2014; 94 (3): 390-5. doi: 10.1016/j.pec.2013.10.025.
11. Vahratian A, Smith YR, Dorman M, Flynn HA. Longitudinal depressive symptoms and state anxiety among women using assisted reproductive technology. *Fertility and Sterility* 2011; 95 (3): 1192-4. doi: 10.1016/j.fertnstert.2010.09.063.
12. Messinis IE, Messini CI, Daponte A, Garas A, Mahmood T. The current situation of infertility services provision in Europe. *Eur J Obstet Gynecol Reprod Biol* 2016; 207: 200-4. doi: 10.1016/j.ejogrb.2016.10.004.
13. Verhaak CM, Smeenk JM, van Minnen A, Kremer JA, Kraaijaat FW. A longitudinal, prospective study on emotional adjustment before, during and after consecutive fertility treatment cycles. *Human Reproduction* 2005; 20 (8): 2253-2260. doi: 10.1093/humrep/dei015.
14. Maroufizadeh S, Karimi E, Vesali S, Omani Samani R. Anxiety and depression after failure of assisted reproductive treatment among patients experiencing infertility. *BJOG* 2015; 130 (3): 253-6. doi: 10.1016/j.ijgo.2015.03.044.
15. Jacobs MB, Klonoff-Cohen H, Agarwal S, Kritz-Silverstein D, Lindsay S, Garzo VG. Predictors of treatment failure in young patients undergoing in vitro fertilization. *J Assist Reprod Genet* 2016; 33 (8): 1001-7. doi: 10.1007/s10815-016-0725-1.
16. Ying LY, Wu LH, Loke AY. Gender differences in experiences with and adjustments to infertility: A literature review. *Int J Nurs Stud* 2015; 52 (10): 1640-52. doi: 10.1016/j.ijnurstu.2015.05.004.
17. Rich CW, Domar AD. Addressing the emotional barriers to access to reproductive care. *Fertility and Sterility* 2016; 105 (5): 1124-7. doi: 10.1016/j.fertnstert.2016.02.017.
18. Troude P, Guibert J, Bouyer J, De La Rochebrochard E. Medical factors associated with early IVF discontinuation. *Reprod Biomed Online* 2014; 28 (3): 321-9. doi: 10.1016/j.rbmo.2013.10.018.
19. Van den Broeck U, Holvoet L, Enzlin P, Bakelants E, Demyttenaere K, D'Hooghe T. Reasons for dropout in infertility treatment. *Gynecol Obstet Invest* 2009; 68 (1): 58-64. doi: 10.1159/000214839.
20. Davis OK, Sokol RZ. Introduction: access to fertility care. *Fertility and Sterility* 2016; 105 (5):1111-2. doi: 10.1016/j.fertnstert.2016.03.034.
21. Beatty PT. The concept of need: proposal for a working definition. *Community Development* 1981; 12 (2): 39-46. doi: 10.1080/15575330.1981.9987132.
22. Ezabadi Z, Mollaahmadi F, Mohammadi M, Omani Samani R, Vesali S. Identification of reproductive education needs of infertile clients undergoing assisted reproduction treatment using assessments of their knowledge and attitude. *Int J Fertil Steril* 2017; 11 (1): 20-7. doi: 10.22074/ijfs.2016.4728.
23. Satir DG, Kavlak O. Use of the internet related to infertility by infertile women and men in Turkey. *Pakistan Journal of Medical Sciences* 2017; 33 (2): 265-9. doi: 10.12669/pjms.332.12620.
24. Bennett LR, Wiweko B, Bell L, Shafira N, Pangestu M, Adayana IP, et al. Reproductive knowledge and patient education needs among Indonesian women infertility patients attending three fertility clinics. *Patient Education and Counseling* 2015; 98 (3): 364-9. doi: 10.1016/j.pec.2014.11.016.
25. Verhaak CM, Lintsen AM, Evers AW, Braat DD. Who is at risk of emotional problems and how do you know? Screening of women going for IVF treatment. *Human Reproduction* 2010; 25 (5): 1234-40. doi: 10.1093/humrep/deq054.



26. Pasch LA, Holley SR, Bleil ME, Shehab D, Katz PP, Adler NE. Addressing the needs of fertility treatment patients and their partners: are they informed of and do they receive mental health services? *Fertility and Sterility* 2016; 106 (1): 209-15. doi: 10.1016/j.fertnstert.2016.03.006.
27. Pasch LA, Sullivan KT. Stress and coping in couples facing infertility. *Curr Opin Psychol* 2017; 13: 131-5. doi: 10.1016/j.copsyc.2016.07.004.
28. Lund R, Sejbaek CS, Christensen U, Schmidt L. The impact of social relations on the incidence of severe depressive symptoms among infertile women and men. *Human Reproduction* 2009; 24 (11): 2810-20. doi: 10.1093/humrep/dep257.
29. Sepidarkish M, Almasi-Hashiani A, Shokri F, Vesali S, Karimi E, Omani Samani R. Prevalence of infertility problems among Iranian infertile patients referred to royan institute. *Int J Fertil Steril* 2016; 10 (3): 278-82. doi: 10.22074/ijfs.2016.5043.
30. El Kissi Y, Romdhane AB, Hidar S, Bannour S, Ayoubi Idrissi K, Khairi H, et al. General psychopathology, anxiety, depression and self-esteem in couples undergoing infertility treatment: a comparative study between men and women. *Eur J Obstet Gynecol Reprod Biol* 2013; 167 (2): 185-9. doi: 10.1016/j.ejogrb.2012.12.014.
31. Heidari P, Latifnejad R. Relationship between psychosocial factors and marital satisfaction in infertile women. *Journal of Qazvin University of Medical Sciences*. 2010; 14 (1): 26-32. (Persian)
32. Corbin J, Strauss A. *Basics of qualitative research* 3e. 1<sup>st</sup> ed. Tehran: Andeshesh Rafie; 2013. (Persian)
33. Jafarzadeh-Kenarsari F, Ghahiri A, Zargham-Boroujeni A, Habibi M. Exploration of the counseling needs of infertile couples: a qualitative study. *Iran J Nurs Midwifery Res* 2015; 20 (5): 552-9. doi: 10.4103/1735-9066.164506.
34. Machin L. A hierarchy of needs? Embryo donation, in vitro fertilisation and the provision of infertility counselling. *Patient Education and Counseling* 2011; 85 (2): 264-8. doi: 10.1016/j.pec.2010.09.014.
35. Bergart AM. The experience of women in unsuccessful infertility treatment: what do patients need when medical intervention fails? *Social Work in Health Care* 2000; 30 (4): 45-69. doi: 10.1300/J010v30n04\_04.
36. Sylvest R, Furbringer JK, Schmidt L, Pinborg A. Infertile men's needs and assessment of fertility care. *Upsala Journal of Medical Sciences* 2016; 121 (4) 276-82. doi: 10.1080/03009734.2016.1204393.
37. Bryson CA, Traub AI. Post IVF Syndrome? Psychological implications of failed IVF. *Obstet Gynaecol* 2002; 4 (4): 201-4. doi: 10.1576/toag.2002.4.4.201.
38. Khalili MA, Kahraman S, Ugur MG, Agha-Rahimi A, Tabibnejad N. Follow up of infertile patients after failed ART cycles: a preliminary report from Iran and Turkey. *Eur J Obstet Gynecol Reprod Biol* 2012; 161 (1): 38-41. doi: 10.1016/j.ejogrb.2011.11.025.
39. Kim H, Sefcik JS, Bradway C. Characteristics of qualitative descriptive studies: a systematic review. *Research in Nursing & Health* 2017; 40 (1): 23-42. doi: 10.1002/nur.21768.
40. Lee GL, Hui Choi WH, Chan CH, Chan CL, Ng EH. Life after unsuccessful IVF treatment in an assisted reproduction unit: a qualitative analysis of gains through loss among Chinese persons in Hong Kong. *Human Reproduction* 2009; 24 (8): 1920-9. doi: 10.1093/humrep/dep091.
41. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse education Today* 2004; 24 (2): 105-12. doi: 10.1016/j.nedt.2003.10.001.
42. Polit D, Beck C. *Essentials of nursing research methods, appraisal and utilization*. 6<sup>th</sup> ed. Philadelphia: Lippincott Williams Wilkins; 2006.
43. Karaca A, Unsal G. Psychosocial problems and coping strategies among Turkish women with infertility. *Asian Nurs Res* 2015; 9 (3): 243-50. doi: 10.1016/j.anr.2015.04.007.
44. Latifnejad Roudsari R, Allan HT. Women's Experiences and Preferences in Relation to Infertility Counselling: A Multifaith Dialogue. *Int J Fertil Steril* 2011; 5 (3): 158-67.
45. Greil AL, Slauson-Blevins K, McQuillan J. The experience of infertility: a review of recent literature. *Sociology of Health & Illness* 2010; 32 (1): 140-62. doi: 10.1111/j.1467-9566.2009.01213.x.
46. Latifnejad Roudsari R, Allan HT, Smith PA. Iranian and English women's use of religion and spirituality as resources for coping with infertility. *Human Fertility* 2014; 17 (2): 114-123. doi: 10.3109/14647273.2014.909610.
47. Latifnejad Roudsari R, Rasolzadeh Bidgoly M, Mousavifar N, Modarres Gharavi M. The effect of collaborative counseling on perceived infertility-related stress in infertile women undergoing IVF. *The Iranian Journal of Obstetrics, Gynecology and Infertility* 2011; 4 (4): 10. (Persian)
48. Rasoulzadeh Bidgoli M, Latifnejad Roudsari R. The Effect of the collaborative infertility counseling model on coping strategies in infertile women undergoing in vitro fertilization: a randomized controlled trial. *International Journal of Women's Health and Reproduction Sciences* 2018; 6 (1): 8. doi: 10.15296/ijwhr.2018.09.
49. Roudsari RL, Bidgoli MR. The effect of collaborative infertility counseling on marital satisfaction in infertile women undergoing in vitro fertilization: a randomized controlled trial. *Nurs Midwifery Stud* 2017; 6 (2). doi: 10.5812/nmsjournal.36723.
50. Bennett LR. Infertility, womanhood and motherhood in contemporary Indonesia: understanding gender discrimination in the realm of biomedical fertility care. *Intersections* 2012; 1 (28).
51. Dyer SJ, Abrahams N, Mokoena NE, van der Spuy ZM. 'You are a man because you have children': experiences, reproductive health knowledge and treatment-seeking behaviour among men suffering from couple infertility in South Africa. *Human Reproduction* 2004; 19 (4): 960-7. doi: 10.1093/humrep/deh195.
52. Taghipour A, Karimi FZ, Roudsari RL, Kimiaei SA, Mazlom SR, Amirian M. Women's perceptions and experiences of the challenges in the process of male infertility treatment: a qualitative study. *Electronic Physician* 2017; 9 (5): 4349-4356. doi: 10.19082/4349.
53. Yebei VN. Unmet needs, beliefs and treatment-seeking for infertility among migrant Ghanaian women in the Netherlands. *Reproductive Health Matters* 2000; 8 (16): 134-141. doi: 10.1016/S0968-8080(00)90195-2.
54. Bazeghi F, Baradaran HR. The role of non-governmental organisations in the management of separated and unaccompanied children, following disasters in Iran. *BMC Res Notes* 2010; 3 (1): 256. doi: 10.1186/1756-0500-3-256.
55. Cardozo ER, Neff LM, Brocks ME, Ekpo GE, Dune TJ, Barnes RB, et al. Infertility patients' knowledge of the effects of obesity on reproductive health outcomes. *American Journal of Obstetrics and Gynecology* 2012; 207 (6): 509.e1-e10. doi: 10.1016/j.ajog.2012.08.020.

56. Giahi L, Mohammadmoradi S, Javidan A, Sadeghi MR. Nutritional modifications in male infertility: a systematic review covering 2 decades. *Nutrition Reviews* 2016; 74 (2): 118-30. doi: 10.1093/nutrit/nuv059.
57. Alfred A, Ried K. Traditional Chinese medicine--women's experiences in the treatment of infertility. *Australian Family Physician* 2011; 40 (9): 718-22.
58. Novak BJB, Berek J, Berek & Novak's gynecology. 14<sup>th</sup> ed. Tehran: Golban; 2007. (Persian)
59. Hadizadeh-Talasaz F, Roudsari RL, Simbar M. Decision for disclosure: The experiences of Iranian infertile couples undergoing assisted reproductive donation procedures. *Human Fertility* 2015; 18 (4): 265-75. doi: 10.3109/14647273.2015.1076579.