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Experiences of Turkish women about infertility treatment: A qualitative study

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Abtract

Objective: To analyze the experiences of infertile women regarding their treatment process and what their expectations were of nurses who cared for them.
Methodology: It is an exploratory qualitative study. The study was conducted in a private and public hospital. The sampling involved twenty-one women diagnosed with primary infertility. The data were collected through one in-depth interview and analysed by means of qualitative thematic analysis.
Results. Themes and sub-themes were identified regarding the experiences of infertile women who were in assisted reproductive care. The themes were physical and emotional difficulties, partner relationships, family and social environment relationships, bureaucratic procedures, financial/monetary difficulties, and what expectations women had of their nurses in this process.
Conclusion. It was determined that women experienced difficulties in all stages of the treatment process. It is suggested that women should be informed in every stage of their treatment and consultation should be performed by the nurses specialized in the field of infertility.

Key Words: Assisted Reproduction Technology (ART), Infertility, Nursing, Qualitative Study, Turkish Women.

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Introduction

Infertility is a disorder of the reproductive system that is defined by the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse (1). It is estimated that 9% of couples worldwide are infertile and 56% of receive medical treatment to promote conception (2). Couples who undergo assisted reproductive processes report feeling psychologically threatened and emotionally stressed. The diagnostic and treatment procedures are considered economically expensive, painful and comprise a complex life crisis (3).

Prior studies of infertile women who seek treatment are exposed to many difficulties. The women sense a constant pressure to become pregnant and their daily lives change. They look to the future with doubt and sense a loss of naturalness in sexual (4-7). Women state that they have experienced negative interactions with the clinics where they receive treatment (3, 6, 8-11). Assisted reproduction technology (ART) involves invasive procedures and presents other difficulties, such as increasing the expectations of what infertility clinics can provide (12). Studies conducted with couples starting in vitro fertilization (IVF) treatment found that the IVF treatment produced the same psychological effects as infertility. In Turkey, infertility is a difficult diagnosis for women to receive. Culturally, all women are assumed to be able to conceive. There are no reliable statistical data regarding but there is an estimated rate of nearly 8.5% of (13). When women cannot conceive, they may apply to ART clinics for assistance. At the time of this study, there were 121 ART clinics within the country and the number increases daily (14). Because ART is both physically and psychologically stressful for women, health staff working in ART clinics should be aware of what women experience. Nurses are the most frequently encountered staff and are vital to helping women have better care. Unfortunately, few studies have been published regarding the experiences and expectations of Turkish women who seek ART treatment. It is assumed that if nurses know what women commonly feel or encounter in the treatment process, the nurses can help to facilitate the women's experience. The aim of this study is to analyze the experiences of women who seek ART and to identify what their expectations are of nurses who work with infertile women.

Methods

The research took place over a six-month period in one private and one county hospital which are in İzmir, Turkey. Both hospitals have an infertility unit.

Design

A purposive sampling method was used (15, 16). Sampling criteria were women **1)** diagnosed with primary infertility; and **2)** had received at least six months of ART. A total of 21 women agreed to be interviewed. This was deemed an adequate sample because, by the twenty-first interview, no new information was presented and repetition and confirmation of previously collected data occurred (15, 16). A qualitative approach was chosen since it is considered to be the most appropriate method for determining an individual's feelings, interactions and perceptions (17).

Data collection

Participants underwent one semi-structured in-depth interview. This method, compared with the structured interview technique, allows for flexibility and makes it possible to ask additional and more detailed questions (15, 17, 18). Socio- demographic data was obtained from a personal information form. An expert view and an open-ended interview guide were prepared to aid the interviewee. Duration of the interview changed according to the participant and each interview lasted between 30 to 50 minutes. Audiotape consent form was taken from each woman.

Interview Questions:

1. Could you tell me about your experiences during infertility treatment?
2. What was the most worrisome event/situation in the treatment process?
3. What are your expectations from nurses working in infertility clinics?

Analysis

The audiotape recordings of interviews were transcribed verbatim and verified for accuracy. Data were evaluated using "thematic analysis." Themes, ideas, and concepts that appeared in the interview transcripts were identified and code words defining and referencing these themes were developed (15, 16).

Some signs used to express non-verbal communications were silence (…), stopping, section (//), emphasis (*……*), and these behaviors were shown as they are. Participants each underwent nonverbal reactions are shown as "(laughed), (cried)" (16). Ages of the interviewed women, length of infertility and the treatment style at the time of interview were shown at the end of sentences with the "{}" sign.

Trustworthiness

The criteria suggested by Lincoln and Gubba (1985) were taken into consideration for evaluating the validity and reliability of the research. Data collection was continued until data satisfaction was obtained. The researcher also took notes about his observations and experiences. In every stage of the research, and during the analyzing statement, both researchers continually discussed themes and subthemes. This enabled the surface of authors' assumptions, biases and ambiguity to contribute to the clear interpretation of the data (15, 19-22)

Ethical considerations

Ethical Committee consent was received from Dokuz Eylul University, School of Nursing Ethical Committee and written consent was obtained from where the study would be conducted. All participants were informed that their participation was voluntary, their names would be concealed, and interviews would be saved. All subjects gave consent to participate.

Results

As a result of interviews, the experiences of women were collected under eight themes and sub- themes (Table I).

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Table I: Theme and sub-themes.

Physical experiences ▪ **Pain**
Emotional experiences ▪ Body image ▪ Fear ▪ Worry ▪ Hope-hopelessness
Partner relationship
Family and social environment
Bureaucratic procedures
Financial/monetary difficulties
Expectations of nurses ▪ *Communication* ▪ *Counseling* ▪ *Being cared for* ▪ *Trust* ▪ *Wishing to see the same nurse in the process of treatment*

Physical Experiences

Pain: Some of the women expressed that they had a lot of pain during the hormone injections.

"Actually using the drugs is a very difficult period // Injections into the abdomen causes pain and abdominal muscles hurt after the injection." {aged 24, 6 years, IVF-ET}

Emotional Experiences

Body image*:* Some of the women expressed that injections negatively affected their body image and they felt disturbed with this situation.

"I had problems with injections. I felt much stressed; because of these injections my abdomen was bruised." {aged 30, 10 years, IVF-ET}

Fear: Few women indicated that they were afraid that the side effects of the drugs may lead to future health problems.

"I am afraid if the medicine I take is dangerous for my life and whether something bad happens. I also fear from the diseases that may occur in 40-50 years. I read the side effects and prescriptions of them, but I still fear." {aged 32, 4 years, IVF-ET}

Some of the women expressed that they did not want to inject themselves. For that reason someone else (partner, mother, friend) did the injection for them.

"I don't inject the drugs myself, I can not, I dare not to inject myself. {aged 24, 6 years, IVF-ET}

Most of the women said that they had problems with taking time off from their work.

"For example, I only had problems in taking day off...I feel disturbed and stressful while asking for day off." {aged 32, 5 years, IVF-ET}

Worry: Most of the women stated that they experienced ambiguous feelings while waiting for the pregnancy result and felt stressed about these feelings.

"How it will be done, what will be done, will it be done so or otherwise, whether it will be done or not caused so much stress for me." {aged 32 , 5 years, IVF-ET}

Hope-hopelessness: All of the women related that they felt very sorry, disappointed and desperate when the treatment failed. Women expressed that the most worrisome event in this process was the failure of the treatment.

"It is a very bad thing, I hope something...I get depressed and disappointed." {aged 24, 4 years, IVF-ET}

Partner Relationships

Most women stated that the treatment process had a positive affect on their relationship, but some expressed a negative effect. They related that ART is difficult for women because of the many invasive procedures and stress. The stress affected their relationship with their partner. Most women said that they were only having sexual intercourse in order to have a child.

"It had no negative effect; on the contrary we behaved well to each other. He supports me and I support him, we encourage each other...We stick heart and soul to each other." {aged 32, 4 years, IVF-ET}

"We felt as if we were being controlled by the doctor when we first started treatment. We were talking with my friends that my husband has sex when the doctor allows and he does not have sex when the doctor gives no permission. I feel under control (laughed) and having sex with the permission of the doctor. {aged 33, 2 years, IVF-ET}

Family and Social Environment

Family: Most women expressed that they were supported by their families.

"Very good, my mother and father support me very much, they support me spiritually as well". {aged 31, 10 years, IVF-ET}

Most of the women explained that they were supported by their partner's family; some of them said that they received negative reactions and some stated that they did not explain to their families that they were getting treatment.

"Yes, I was having problems with my husband's family because I have no baby. They tell my husband to get divorced since I have no baby. My husband does not listen to them since he loves me." {aged 30, 10 years, IVF-ET}

Social Environment: All of the women expressed that people in their social environment asked questions about treatments and expressed their views about doctors and clinics.

Some women did not share that they had started treatment and avoided people who might ask questions and show curiosity about her childbearing.

"Because everyone says something... Nonsense questions... Everyone suggests somebody. Go this place, see this doctor, go this hospital, do this and that." {aged 31, 7 years, IVF-ET}

Bureaucratic Procedures

Most of the women related that they had problems due to bureaucratic transactions and procedures.

"I don't know...Dealing with this processes was like a waste of time. It is a waste of time, it makes me distressed." {aged 32, 5 years, IVF-ET}

Financial/Monetary Difficulties

Most of the women discussed that they had financial difficulties in the treatment process.

"We spend all our money for the drugs, doctor, hospital, I have no saving and no support. I save all the money for drugs, doctor and treatment." {aged 33, 10 years, IVF}

Expectations of Nurses

Communication: Most of the women stated that they expected nurses to be more cheerful and understanding supportive and empathetic.

"I expect them to be more understanding and cheerful. Or they can approach us more in a friendly manner. {aged 32, 5 years, IVF-ET}

Counseling: Most women expressed that they expected counseling from nurses and same women that they would overcome this process when they receive counseling.

"Not knowing what enterprises are applied causes fear and stress for me". {aged 32, 4 years, IVF-ET}

Being cared for: Some women expressed that they expected the nurses to show more concern and to care for them by chatting and supporting them spiritually.

"If they speak to patients it would be better, patients would relax. We come to hospital, they only say "Bring this document and do this, do that (laughed) that is it, nothing else." {aged 32, 5 years, IVF-ET}

Trust: One of the women expressed that she wanted to be able to trust the nurse who is responsible for her treatment.

"I want her to be reliable. Because this is health problem and I should trust the nurses..." {aged 32, 3 years, IUI}

Wishing to see the same nurse in the treatment process: A few women expressed that it was difficult to not have the same nurse in the clinic, where they received treatment. They felt that this affected them negatively.

"Nurses should be familiar to us, change of nurses affect us negatively." {aged 32, 4 years, IVF-ET}

Discussion

Women shared that they felt pain during the invasive procedures, injections, hysterosalpingography (HSG), oosite pick-up (OPU), and intrauterine insemination (IUI). The literature supports these findings and adds that these procedures are highly stressful, cause pain and physical disturbances (4, 6, 7). The use of pharmacological and non-pharmacological methods to prevent pain is very limited and the counseling services are insufficient. The women in this study said that injections caused stress and had a negative effect on their body image. Prior research has documented that self-injection is a traumatic procedure (4, 6, 7) and helps to emphasize why the health care staff needs to pay more attention to body image.

Women expressed a fear for the side effects of hormone drugs and similar findings have been reported in the literature (6). The fear can be due to the complexity of the drug application, fear of making a mistake, insufficient information, and lack of self-confidence. Another fear that women shared was losing their jobs because ART treatment can negatively affect business life and employers (4). Private infertility clinics have more flexible working hours and will accommodate the work demands of women.

The working hours of formal institutions are strict and unchangeable. Women start treatment with the hope and expectation for success after embryo transfer (ET). Waiting for the result of the study causes anxiety and is one of the most anxious periods for women (4- 7). The stress is compounded by the fact that women do not receive sufficient support and counseling during this time. Failure of treatment was the most worrisome event for women. Researchers found that it was one of the events that worries women the most (5, 4)

In Turkey, the result of a treatment is told to the patient by doctors who do not provide an opportunity for women to express their feelings and thoughts. In the treatment process, women can not be prepared for the positive and negative result of the treatment. Physicians do not take the time to prepare women for unsuccessful treatments. Therefore, when the treatment fails, women feel exhausted and worn out, thinking that all their efforts and financial resources go for nothing. More than half of the women expressed that they felt support from their husband during the process and that the women gained power from their shared experience. This result is contrary to the literature which shows that most partners are negatively affected (4,8, 6, 12, 23). This finding can be partially explained by the

younger age group. Other subjects stated that treatment had a negative affect on their relationship and sexual life. The literature notes that the sexual life of women is negatively affected when actively trying to conceive (8, 4, 6, 12, 23).

This is in part to partners trying to have sexual intercourse during the ovulation days; doctors directing a schedule of sexual intercourse during ovulation; sexual abstinence before sperm analysis, and other restrictions on the sexual life of women. Women implied that they receive support from their own families but not from their husband's families. In Turkey, having grandchildren is very important for the man's family. If their son does not have any children, it is very embarrassing. This study identified that women find it difficult to be asked about their infertility.

Studies indicate that women without children are frequently exposed to questions related to infertility and treatment process (4, 6, 7, 12). In Turkey, social status comes with being a parent. There is a sense of power for men who have children and stigma for women who cannot conceive.

For that reason, infertile women feel more pressure by society, their husbands, and his family to seek ART treatment. Infertile women tend to develop defense mechanisms, such as not telling about receiving treatment or avoiding certain social environments. This study and other researchers have found that women feel stressed while performing bureaucratic procedures. These procedures include when couples have to prepare government documents in order to receive treatment. [6] Women worry about the costs of treatment and will often restrict some of their needs or become indebted in order to continue treatment. This is a common finding with infertility treatment (4-7). In Turkey, financial problems are common because infertility treatment is expensive and there is limited money paid by the government and insurance. When compared to other team members, the nurse is considered as the most important health staff member that couples meet and contact most frequently. This gives nurses an unique role in the infertility team (24) and their roles should change in time (25). Nurses' knowledge, skill, responsibility, and autonomy should increase (26). Some consider that the most important role of nurses is to provide direct patient care (27, 28). Women shared that they wanted to work directly with their nurses, to receive counseling and care in all stages of treatment. Instead, the women experienced difficulty with the nursing care, communication styles, technical skills, and lack of emotional closeness (29). These findings can be explained with the current roles and responsibilities of nurses working in infertility clinics in Turkey. There are a limited number of nurses in the clinics and they are responsible for more than just patient care. Their broad responsibilities prevent nurses from performing more professional roles.

Conclusions

This study found that women experienced difficulties in all stages of ART treatment (e.g., drug therapy, diagnosis, treatment, bureaucracy). Women also had difficulties because of the effects of treatment on their lives. This study provides important insights into how a health staff can better understand the difficulties experienced by infertile women in Turkey. At the same time, it is also important in that it allows nurses and patients worldwide to see how certain difficulties in treating infertility are universal. The difficulties that women experience during their treatment period must be defined by preparing definition forms. It is suggested that specialty nurses consult with the women and their husbands in every stage of their treatment and consultation.

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