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Perception of Female Identity in Women with Premature Ovarian Insufficiency: A Qualitative Study

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Abstract

Background: Premature ovarian insufficiency (POI) occurs in women before the age of 40. Although the outcomes of POI in women include its adverse effects on general health, sexual-reproductive health, and finally reduced quality of life. One of the first adverse consequences is a threat to female identity of the patients. The purpose of the present study was to investigate the perception and experience of women with POI about female identity.

Methods: In this qualitative study, interviews were conducted with 15 women having POI. Data included participants' recorded voices that were analyzed using conventional content analysis.

Results: After content analysis of the interviews with a focus on the perception and experience of women with POI about female identity, four categories emerged; they included the failure in realization of motherhood dream, the importance of menstruation, construction of female identity, and attempts to normalize the situation.

Conclusion: After analyzing the emerged categories obtained by interviewing with POI women, it seems that physicians need to pay special attention to the distortion of the female identity of these patients and educate the medical team about the importance of the effect of treatment on improving their emotional health.

Keywords: Female identity, Primary ovarian insufficiency, Qualitative research.
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Introduction

Premature ovarian insufficiency (POI) is a hypo-estrogenic state that is accompanied with the development of hypergonadotropic hypogonadism and occurs in women before the age of 40 (1). The prevalence of POI is 1-3% in women below 40 years of age and around 0.1% in women under 30 (2). This disorder affects women physically, psychologically, socially, and sexually and results in irregular menstruation, symptoms of premature menopause, infertility, osteoporosis, endocrine and cardiovascular diseases (3), anxiety, depression (4-7), and impaired self-esteem (8-10). Although the final outcome of POI in women culminates in its adverse effects on general health, sexual and reproductive health, and consequently reduced quality of life (11-13), one of the worst adverse consequences is the threat to the female identity as a result of women perception and experience of altered womanhood after diagnosis of POI (14).

Identity is defined as the qualities, beliefs, personality traits, appearance, and/or expressions that

characterize a person. In psychology, the term "identity" is most commonly used to describe personal identity or the distinctive qualities or traits that make an individual unique (15, 16). Identities are strongly associated with self-concept, self-image (one's mental model of oneself), self-esteem, and individuality (17, 18). Individuals' identities are embedded, but can also be contextual, situationally adaptive, and changing. Although the character of individuals is a context-bound issue with a fluid nature, identities are often perceived as if they are invariable categories picturing an individual due to their grounding in the definition of personal identity (the sense of being a continuous and persistent self). Our physical body is viewed by others in the society and is the vehicle through which we act in the world. Therefore, it seems likely that changes in the body in case of POI may impact valued aspects of identity for women (14).

Women with POI feel imperfect due to infertility and think they are older than other women. Motherhood and childbearing are part of women's identity in some cultures such as Iran. Therefore, infertility impacts components of female identity as personal, social, and family elements (19). On the other hand, amenorrhea and menopause symptoms make women think they are different from others and do not feel feminine and embrace womanhood (20).

Some qualitative research has been conducted on the identity of women; for example, Charmaz in a qualitative study showed how chronic illnesses disrupt dominant assumptions about equivalence between the body and self (21). Some women in Hunter and O'Dea's study explained that menopause symptoms affected their body but their self-perception remained unchanged (22). Similarly, Martin described women speaking about menstruation, childbirth, and menopause as biological processes not attributed to their gendered bodies (23). Beauvoir demonstrated the loss of hope for the future that women may feel at losing female fertility (24). Sergeant recently, in a Grounded Theory study, assessed women's identity during menopause. The study shows a biomedical discourse and a focus on women as child-bearers and menopause as a marking transition to another phase of life. Minnaar in a study entitled "is ovarian cancer the end of womanhood?" showed that social notions of motherhood influence the ideology of womanhood socially, emotionally, and psychologically, which implicates how women understand their own femininity, sexuality, and their bodies (25).

Although some qualitative research has been conducted on the identity of women, the target group in these studies included only women with cancer or postmenopausal women; therefore, the perception and experiences of women with POI about their female identity have not been studied (14, 25-27). If the treatment staff become aware of the concerns of these patients, they will surely help to improve their health by providing correct information to the patients and removing their doubts and misconceptions. Therefore, the purpose of the present study was to investigate the perception and experience of women with POI about their female identity.

Methods

Subjects: In this study, the participants were selected from women with POI who were referred to Avicenna Fertility Affiliated to Avicenna Research Institute Center and Valiasr Reproductive Health Research Center Affiliated to Tehran University of Medical Sciences. Inclusion criteria were as follows: married women with POI, awareness of the procedure, Iranians and Persian speakers, literate women, and lack of previous participation of cases in qualitative interviews. Diagnostic criteria for POI included experiencing amenorrhea for at least 4 months before the age of 40 with two serum FSH levels greater than 25 *mIU/ml*, measured at least in a one-month interval (28) and subsequently confirmed by a gynecologist.

Interviews were conducted with the collaboration of the centers' staff and patients' consent for participation in the study was obtained, while the confidentiality of the individuals was maintained. Targeted sampling was performed with maximum sampling diversity in terms of age, education, and equality and continued until data saturation (29).

Data collection and measurement: In this study, interviews were conducted using in-depth and semi-structured interviews. First, the purpose of research was explained to the participants and they were informed that the interviews would be recorded but the audio recording could be interrupted on their request. They were also assured that their personal information would be kept confidential. The type of guiding questions was determined based on the target group and all were asked precisely in the interviews. The guiding questions for the interviews were prepared according to the suggestions of professors of the research team and

ethics experts over time and by analyzing the data obtained from the interviews. In other words, with the passage of time, the process of designing guiding questions became more specific. Some of the interview questions were as follows:

1. What is your understanding and experience of premature ovarian insufficiency?
2. How do you define premature ovarian insufficiency?
3. What is your desire and experience regarding pregnancy and having a child with premature ovarian insufficiency?
4. What changes do you feel with premature ovarian insufficiency in your relationships with your spouse and parents?
5. What is your desire and experience of sex after being diagnosed with premature ovarian insufficiency?
6. What is your desire and experience of social relations in society and relations with relatives after being informed of premature ovarian insufficiency?

Depending on the interview process, the order of the questions was different for all participants. To make the interview comprehensible as well as clarify the statements, several ancillary questions were asked such as "Would you explain more clearly?" and "What do you mean?". The interviews began in May 2020 and ended in May 2021, lasting between 50 and 110 *min* (mean of 53 *min*). Participants were then asked about personal information such as age, education, occupation, age of women at the time of the disorder, duration of POI, number of pregnancies, number of children, number of failed pregnancies, and type of pregnancy (spontaneous pregnancy-conception through egg donation).

Sampling method and sample size: There is no exact criterion for determining the sample size in qualitative studies. According to Polit, the sample size and duration of data collection are confirmed during the implementation of the study (30). Although the adequacy of the sample size in qualitative research is a relative and subjective matter, the sample should not be too small or large. The sample size in qualitative studies is usually determined based on the need for information. In fact, the researcher continues sampling until reaching data saturation, that is, until no new information is obtained and the data is repeated. One of the targeted strategies of qualitative studies is sampling with maximum diversity, which includes the conscious selection of samples with a large and wide variety in the investigated range. Therefore, the sampling method in this study was purpose-based considering the maximum diversity; in fact, the researcher carefully and consciously selected the best cases who could optimally cooperate with the research team and provide proper information. In this study, after interviewing 13 participants, data saturation was achieved so that the classes and sub-classes were completed and new information did not appear in the form of new categories; for more confidence, two more interviews were conducted with a total of 15 people. Finally, the data analysis ended with the same number of interviews.

Ethical approval for this study (IR.TUMS.FNM.REC.1398.018) was granted by the Ethics Committee of the School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran.

Data analysis: Qualitative data was analyzed using conventional content analysis (31) based on the method proposed by Zhang and Wildemuth (32) in eight stages including preparing data for qualitative content analysis, making decision on the unit of analysis, categorizing, testing code on a sample of text, extending the process of test coding to the entire text, having access to encoding stability, making conclusion from classified or coded data and reporting stage (32, 33).

For this purpose, at the first step and after each interview, the recorded data were transcribed verbatim. To be immersed in the data, the transcript needed to be read repeatedly by the lead researcher. In addition, participants' nonverbal messages such as tone, silence, crying, and note-taking were added to the text during the interview. At this stage, due to some incomplete explanations by the participants, the researcher decided that more additional interviews were needed with one participant. As a result, the main researcher interviewed this participant twice.

In the next step, the initial codes were extracted from the units (participants' quotations). Then, based on the similarities of these codes, subcategories were formed and finally main categories were constructed. The researcher coded a sample of the text and the consistency of the data coding was monitored by three members of the research team. After agreement about the stability of coding, an iterative process was accomplished and the coding process was extended to the whole text.

Coding stability (initial codes and subcategories) was rechecked by three members of the research team and experts in the field of qualitative research. Finally, the subcategories were tested on a wide range of data. Thus, the explanation of female identity subcategories in women with POI was obtained and MAXQDA software, version 12, was used to manage the data in the qualitative stage of the research. The final step consisted of reporting and interpreting the formed categories.

Data trustworthiness: The most widely used criteria for assessing reliability in the qualitative content analysis are those developed by Lincoln and Guba. They have proposed four criteria (credibility, dependability, conformability, and transferability) for evaluating the trustworthiness of qualitative research (34). In the present study, reliability for the main stages of qualitative content analysis from data collection to reporting results was defined as follows (35):

1) the credibility of the data was confirmed through targeted sampling with maximum diversity, control of data by participants, double-check of interviews, codes, and categorizations extracted by members of the research team, and long-term interaction with participants; (2) to check the dependability, the researcher provided the results of the research to an external observer to audit the research and besides that, the same questions were asked of all participants so as to reduce the risk of instability and inconsistency in research data collection; (3) external compatibility was confirmed using an external review; and (4) to check transferability, the researcher tried to make it possible for other researchers to follow the research path and work steps by accurately recording the research path, decisions, and writing them. Therefore, with a detailed description of the participants, sampling method, and time and place of data collection, the readers will be able to make a correct decision about the transferability of the findings if they want to apply these findings in another context and situation. Also, in this research, in order to provide more transferability of data, samples with maximum variability in terms of age, level of education, economic and social status, medical history, and duration of illness were selected.

Results

In the current study, 15 women with POI, aged from 22 to 46 years, and POI duration of 1-23 years were interviewed. The age range of women at the time of definitive diagnosis of POI was a minimum of 13 and a maximum of 40 years. Among the participants, two women were divorced due to infertility as a result of POI. The demographic and reproductive characteristics of the participants are presented in table 1.

After content analysis of the interviews with a focus on the perception and experience of women with POI aboutfemale identity, 4 categories and 16 subcategories emerged. Table 2 shows the categories and subcategories of the research. They include failure in the realization of motherhood dream, menstruation as an important life event, construction of mother identity, and attempts to normalize the situation.

Failure in the realization of motherhood dream: The results showed that all participants were concerned about impairment in fertility and it was the

Table 1. Demographic and reproductive characteristics of the participants

Characteristics	Mean (range)
Age (year)	38.06 (22-46)
Age at the time of definitive diagnosis (year)	27.62 (13-40)
POI duration (year)	8.5 (1-23)
Characteristics	Number (percentage)
Education	
Primary	4 (26.66%)
Diploma	5 (33.33%)
Bachelor’s degree	2 (12.5%)
Master’s degree	2 (13.33%)
PhD degree	2 (13.33%)
Occupation	
Housewife	10 (66.66%)
Employed	5 (33.33%)
Pregnancy history	
Yes	8 (53.33%)
No	7 (46.66%)
Alive children	
Yes	4 (26.66%)
No	11 (73.33%)
Unsuccessful pregnancy history	
Yes	6 (40%)
No	9 (60%)
Type of pregnancy	
Natural	5 (33.33%)
Egg donation	3 (20%)
Not becoming pregnant	7 (46.66%)

Table 2. Categories and codes of "distorted female identity"

Category	Subcategory
1. Failure in the realization of motherhood dream	1. Being upset by observing pregnancy and childbearing of others 2. Psychological damage in observing the pregnancy of others 3. Feeling regretful about pregnancy of others 4. Feeling like falling behind in life
2. The importance of menstruation	1. Attempts to treat the menstruation problems 2. The positive effect of menstruation on health and mood 3. Cessation of menstruation reflects feelings of despair about premature aging 4. Unhappy feelings about menstruation disorder
3. Construction of mother identity	1. Feeling hopeful after the first pregnancy 2. Feeling happy at being noticed by others 3. Desire to become a mother 4. Imagining pregnancy
4. Attempts to normalize the situation	1. Trying to control negative emotions in facing with others' pregnancies 2. Feeling different from the others 3. Comparing their own situation with others 4. Keeping their problem as a secret and keeping up the appearance

most important reason for their consulting with a physician. One of the participants, who had POI for 18 years, sadly said:

"I get very nervous when they tell me that someone is pregnant. I talk to God and say, look how young she is, but she got pregnant sooner than me" (p.5, 31 y).

Another participant who had regular periods for 17 years before POI stated jealously:

"Well, two women in my family, during these 4 years that I had an early menopause, gave birth to their second children, and I had a feeling of jealousy, and it made me think about my problem and I suffered mental illness" (p.8, 35 y).

One participant with POI, who experienced the problem since the age of 37, sadly said:

"I recently heard that a 50-year-old woman is pregnant. I was very sorry… the symptoms of menopause started when I was 43, but this 50-year-old woman is pregnant now, I tell lies to my friend about my menstruation ..., I say, oh, I am having menstruation ... and when I do not menstruate, I say, for example, oh, I have a backache. In fact, I do not want to be different from others" (p.15, 43 y).

Menstruation is an important life event: Another concern seen among affected women was the cessation of menstrual bleeding as menstrual bleeding was important to women and gave them a sense of youth. One of the participants who had regular periods for 24 years and an abrupt shift to amenorrhea said:

"I felt better with hormone therapy when I was menstruating. A sense of calmness and relaxation ... that I am not different from someone who is my age and is having regular periods. Hormone therapy and menstruation made me feel better" (p.9, 43y).

Other participants who had never experienced menarche and menstrual bleeding and were menstruating only with the help of hormone therapy stated:

"Menstruation has a positive effect on my mood. And when I get a period, some of the pressure goes down. I feel calm, my body calms down. When I do not menstruate for a few months, it really affects my mood" (p.14, 27y).

Another participant said nervously:

"The interruption of my period made me feel bad and had a negative energy" (p.6, 36 y).

Construction of mother identity: Patients, for personal reasons as well as social pressure from others, were strongly inclined to become pregnant and experience pregnancy. A participant who had been married for 5 years and had no children tearfully and hopefully explained:

"… If I get pregnant for the first time, I feel hopeful. Because I feel like I'm likely to get pregnant again later. Because I heard a lot that IVF is suitable for getting pregnant for the second time" (p.7, 37 y).

Another woman who married consanguineously 12 years ago stated:

"I had a pregnancy and abortion experience. It was very good and had a positive effect. It had a very positive effect for a year or two. A little bit of hope" (p.1, 30 y).

A patient, who had infertility for 10 years, disappointedly said:

"I try my best to get pregnant because of my husband. Because I love him so much. He is a good person. I would like to have a baby" (p.12, 43 y).

One participant that had a history of two unsuccessful pregnancies with donated eggs said:

"Sometimes I think I'm pregnant and I touch my abdomen and talk to an imaginary fetus" (p.2, 34 y).

Attempts to normalize the situation: Although patients were mostly jealous or envious of seeing others getting pregnant and having children, they tried not to express these negative feelings to others and behaved normally. A patient who had POI for 9 years said:

"I may feel frustrated, but I will not let it affect me" (p.4, 42 y).

Another patient stated:

"In general, when I saw that my colleague is my age, but she does not have this problem, or my colleague, who is 2 years older than me and had no problem, or my sister, who is 49 years old and is still having a period ... these were all things that bothered me" (p.10, 46 y).

A participant that had regular periods for 27 years stated:

"My friend is 48 years old and she is single and we have relationship with each other. My other colleague was forced to remove her ovaries when she was single ... I see that everyone has a problem" (p.3, 46 y).

One participant who had POI from the age of 34 years sadly said:

"I ask myself in private why it should be like this, but I did not reveal anything to anyone" (p.11, 44 y).

Discussion

The aim of this study was an investigation of the perception and experience of women with POI about their female identity; after extracting and coding the data obtained by the interviews, four categories emerged. They included failure in the realization of the motherhood dream, menstruation as an important life event, construction of mother identity, and attempts to normalize the situation.

Female identity is affected by some factors such as the perception of oneself as a woman (self-image) and society's expectation of being a woman. As a result, it is different depending on the sociocultural context in each country (36). In our study, the most important concern in women with POI was the loss of fertility. The first category emerged in our study was a failure in the realization of motherhood dreams; infertility and failure in pregnancy caused patients to fail to realize their motherhood dream. Other studies showed that infertility not only distorts self-image but also threatens feminine identity (19). Similarly, one study showed that these women's conception of femininity changes from a fertile woman to an infertile and post-menopausal one. Moreover, it was revealed that female identity is threatened by distorted femininity and distorted maternal role (37). Orshan et al. showed that these women felt like they were robbed of something (38). Also, Nauman found when women were diagnosed as infertile, they experienced the feeling of "absence" (39). Groff et al. showed that women with POI felt less feminine and more aged (8). Pasquali stated that by losing fertility, participants felt less feminine and attractive than other women (37).

The other concern of participants was the change in menstrual bleeding pattern that threatened the female identity. The second category found in our study was menstruation as an important life event. Menstruation is a biological event that not only reflects femininity of women, but the process helps to confirm the social role of women (40). This is related to attitudes and beliefs about menstruation (40). The occurrence of menopause in Skultans' study caused the change of women roles (social roles of the individual as being a sexual partner, mother, and housewife to being a post-menopausal woman with physical changes) (40). In line with the findings of the present work, another study demonstrated that women wished to menstruate and they believed this contributes to their good overall health and in case of lack of menstruation, their health will be in danger (40). In another study like ours, participants' efforts to treat their menstrual problems were extremely important, and they felt as comfortable as their non-menopausal peers (41). Similarly, in Boughton's study, women were afraid to let others know about their menopause since they hate the feelings of unattractiveness and despair about premature aging (42).

In the current study, participants attempted to demonstrate their maternal identity which was the third category. Nauman pointed to Freud's position in his study who believed that the girls' full identity was reflected when they are able to achieve pregnancy (39) and the importance of reproduction within cultures is directly associated with expectation of pregnancy. Nauman believes pregnancy and childbearing are still important parts of female identity (39). Also, Thorn showed that a women's "role" is more closely tied to the role of motherhood (20, 43). In Beauvoir's study, women felt losing their female identity since their society valued the concept of fertility (24).

The fourth category in our study was an attempt to normalize the situation. Our findings showed that participants try to control negative emotions about others' pregnancies. Similar to our study, some Kuwaiti women with POI confessed their feelings of resentment and jealousy in facing pregnant women (44). The results of some studies showed patients had a sense of inability to be fitted into a social group, or they were sometimes forced to leave or change their jobs due to constant questions (45, 46). These are in accordance with the findings of our study as women felt they were different from others and they compared their own identity with others (47).

Another finding of the current study was hiding the health problem by patients, which has been mentioned in other studies and relates to the fourth category. In this way, women with POI preferred to conceal amenorrhea, infertility, and early menopause from others. Most of them tended to keep the issue of donation as a mutual secret between themselves and their husbands (46). Because the practice of egg donation was considered a stigma, hiding the disease became a major concern among them (48, 49).

The most important limitation of the current study was the problem of sampling in terms of the small number of cases referred to the centers. Also, sampling was associated with the sudden outbreak of the COVID-19 pandemic. As a result, recruitment of cases was exacerbated due to restrictions for physical presence in medical centers and quarantine by the government. As a result of quarantine and closure of infertility centers collaborating in the procedure of patient sampling, and considering the change in the general policies of the government towards the provision of non-face-to-face services, the research team decided to take the following measures in order to overcome several challenges.

The first approach was increasing the number of sampling centers and asking for the collaboration of private sector. Moreover, in order to increase the motivation of the personnel of the mentioned centers for the introduction of clients suffering from POI in the present study, a bonus was considered for the staff who introduced participants to the researchers.

Conclusion

The aim of this study was to investigate the perception and experience of women with POI about female identity; after extracting and coding the data, four categories emerged. They included failure in the realization of the motherhood dream, menstruation as an important life event, construction of mother identity, and attempts to normalize the situation.

Based on the above categories, treatment staff should be aware that POI is not just a medical complaint of patients. Rather, fertility problems, early cessation of menstrual bleeding, and the early onset of menopausal symptoms threaten the female identity of these patients. As a result, physicians need to be aware that by using hormone replacement therapy (HRT) as a treatment procedure, they can improve women's perceptions of their femininity. It is also recommended that psychiatrists in counseling sessions with these patients pay special attention to the distortion of the female identity and educate the medical team about the importance of the effect of treatment on improving the female identity. Finally, health professionals, by removing the factors that threaten women's identity can be helpful in increasing the effectiveness of treatment interventions.

The results of this study can be very useful for physicians and patients and lead to the improvement of the results of therapeutic interventions. If physicians and relatives take care of the patients' emotional health, it can lead to a better understanding and awareness of their feelings. However, the scope of this study was limited to Iranian and Persian-speaking women. Conducting similar qualitative studies in non-Iranian societies may show different results due to cultural and social differences. As female identity is a social construct that varies across cultural contexts, it is recommended that further qualitative studies be conducted in other countries with various sociocultural contexts.

Availability of data and materials: Data sharing is not applicable to this article as all transcripts and recordings were deleted permanently following data analysis to protect the identity and privacy of the participants. The datasets generated and analyzed during the current study are not publicly available to protect confidentiality right. However, they are available on reasonable request from the corresponding author.

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Conflict of Interest

Authors declare no conflict of interest.

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