Infertile Japanese women’s perception of positive and negative social interactions within their social networks

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BACKGROUND: The purpose of this study was to determine positive and negative social interactions experienced by infertile Japanese women. METHODS: Semi-structured interviews were conducted with 24 infertile women. The informants were asked about their experiences of positive (helpful) and negative (unhelpful) social interactions with members of their social networks, excluding their partners, with regard to their infertility. RESULTS: Nine positive social interaction categories were clarified, including listening closely to the distress experienced in infertility and treatment, not prying or interfering with the topic of children and respecting the women’s decision regarding fertility treatment and taking a wait-and-see attitude. Nine negative social interaction categories were also identified, including prying with the topic of children, showing a negative attitude toward infertility or reproductive medicine, being criticized for not having children and avoiding contact. CONCLUSIONS: The present findings systematically and qualitatively determined the positive and negative social interactions experienced by infertile Japanese women within their social networks. This is essential knowledge for medical staff to counsel patients and their family members. To form a supportive social environment for infertile women, we recommend practical measures for health workers and helpful advice with regard to interactions between infertile women and their social networks.

Keywords: infertile women; positive social interaction; negative social interaction; qualitative study; social support

Introduction

It has been nearly 30 years since the first successful IVF. By 2002 in Japan, where the total population was ~120 million, the calculated population of infertile couples had increased to 466,900, 1.6 times that in 1999 (Yamagata et al., 2003). In 2006, the number of facilities providing reproductive medicine was over 500, and 1.79% of total live births were conceived through IVF treatment (Japan Society of Obstetrics and Gynecology, 2008).

It is well known that infertile women experience mental, physical and social distress by not being able to have a child and by undergoing fertility treatment (Bergart, 2000; Cousineau and Domar, 2007). Although their psychological status has been often studied in past research, many studies in particular indicated that women with fertility problems have more depression or anxiety, a lower quality of life, etc., compared with the general population or with fertile women (Wright et al., 1991; Oddens et al., 1999; Fassino et al., 2002) or with those who became pregnant through fertility treatment (Weaver et al., 1997; Kee et al., 2000; Matsumayashi et al., 2001). In addition, their psychological status can differ depending on which stage of treatment cycle they are in (Newton et al., 1990; Slade et al., 1997; Boivin et al., 1998) and how long they have undergone treatment in the past (Berg and Wilson, 1991; Chiba et al., 1997).

It is well known, generally, that social support can positively affect the psychological health of people experiencing stressful life events (Cutrona and Russell, 1990) and similar effects can be expected for infertile women. However, many studies about infertile women’s experiences of social interactions within their social network have revealed that infertile women experienced negative social interactions, such as insensitive remarks or inappropriate support from family and friends (Sandelowski and Jones, 1986; Callan and Hennessey, 1988; Abbey et al., 1991; Imeson and McMurray, 1996). Moreover, it has been shown that unsupportive social interactions are positively associated with infertile women’s psychological distress (Mindes et al., 2003).

In Japan, similar experiences have been reported (The Friends of Finrrage, 1994; Yano and Sakajo, 2000; Akizuki et al., 2004). According to the study of Chiba et al. (1997), nearly half of the subjects perceived what others outside of the family said as stressful, and women who had been undergoing treatment for 4 years or more perceived what family
Materials and Methods

Participants

The participants were infertile Japanese women whose initial consultation had been at least a year previously, and thus who presumably were past the examination stage and into the infertility treatment stage. Participants were recruited through four medical institutions in the Kanto area and also through an infertility-related Internet site. At the medical institutions, requests for research cooperation were made by doctors to patients who met the above criteria, ensuring that there was no bias toward the period and type of treatment. Patients who expressed interest in participating were then approached by a researcher, and after official requests for participation, interviews were conducted with 22 women. In addition, after gaining permission from the website manager, a request for research co-operation was posted on a relevant website bulletin board. A total of five people expressed interest, and after further explanation of the study, one did not reply and two declined due to geographical accessibility, and interviews were eventually conducted with two of these people.

The average age of the 24 participants was 35.5 years (range: 27–44), the average length of marriage 7.5 years (range: 1–20) and the average length of time since the initial consultation was 3.3 years (range: 1–16). In terms of type of treatment, six participants were using the timing method, 11 were undergoing artificial insemination by husband (AIH), three were undergoing IVF–ET and four were undergoing ICSI. In seven cases, the cause of infertility was solely female, in seven cases solely male, in five cases, both male and female and in five cases, the causes were unknown.

Data collection

Semi-structured interviews were carried out between May and August 2001. The main questions were as follows.

(i) Positive social interactions: Tell us about the things that people have done or said that have been helpful or made you feel better with regard to your infertility.
(ii) Negative social interactions: Tell us about the things that people have done or said that did not help (although they may have been trying to help), that upset, angered or hurt you.

The above questions were asked in relation to family members (excluding partner), relatives, friends, colleagues, acquaintances, neighbors and people who have experienced infertility. Interviews were conducted in the participant’s home, hospital interview room or coffee shops, and the average length of the interview was 95 min per person. Interviews were tape-recorded with the permission of participants, and conducted to be as unobtrusive as possible to the participant’s thinking and utterances.

Ethical considerations

The purpose and overview of the study was explained at the time of request and before the interview, and interviewees were informed that their participation was entirely voluntary, their anonymity would be assured, they could withdraw from the study at any time and the information that they will be providing would be used solely for the purposes of the study. They were also told that the researcher would assume responsibility for the safe-keeping of the data, and that they could request deletion of their data at any point.

Analysis

Recorded tapes were transcribed verbatim and read repeatedly. Lofland and Lofland (1995) data analysis procedures were referred to as a basis for analyzing the 87 positive social interaction episodes and 91 negative social interaction episodes. First, details of what members of the participant’s network said or did, their attitudes, and how the participants responded and perceived them were distinguished in each episode. Then, the meaning of each episode was made clear and a label corresponding to the semantic content of each social interaction was assigned. Finally, categories were defined with labels with similar semantic content and a label that appropriately represents the meaning of each category was attached. Generally, the first author was involved in these analytic processes. In order to ensure the credibility of results, peer debriefing was carried out by ways such as continuous discussions among co-authors and between them and other researchers throughout the study process. Also, the results were checked as to whether they were valid by midwives with plenty of experience in nursing of infertile patients.

Results

The analysis resulted in nine categories of positive social interactions and nine categories of negative social interactions (Table I). Each category will be described below. Participant utterances are signaled using double quotation marks (""), whereas utterances by participants said on behalf of the others are indicated by single quotation marks (‘’).
Extra contextual information is provided in square brackets ({}). The participant’s age, length of time receiving treatment and type of treatment are indicated at the end of the quotes ({}).

**Table I. Categories of positive and negative social interactions.**

<table>
<thead>
<tr>
<th>Positive social interactions</th>
<th>Negative social interactions</th>
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</thead>
<tbody>
<tr>
<td>Listening closely to the distress experienced in infertility and treatment</td>
<td>Not listening to the distress experienced in infertility and treatment</td>
</tr>
<tr>
<td>Showing understanding and sympathy toward the distress of infertility and treatment</td>
<td>Not showing understanding and sympathy toward the distress of infertility and treatment</td>
</tr>
<tr>
<td>Providing encouragement at difficult times</td>
<td>Not providing encouragement at difficult times</td>
</tr>
<tr>
<td>Showing concern and interest</td>
<td>Not showing concern and interest</td>
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<tr>
<td>Not being disappointed about the infertility</td>
<td>Not being disappointed about the infertility</td>
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<tr>
<td>Providing useful information about fertility treatments</td>
<td>Providing useless information about fertility treatments</td>
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<tr>
<td>Providing material support</td>
<td>Providing material support</td>
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<tr>
<td>Prying with the topic of children</td>
<td>Prying with the topic of children</td>
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<td>Interfering where the topic of children are concerned</td>
<td>Interfering where the topic of children are concerned</td>
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<tr>
<td>Offering inappropriate advice and concern</td>
<td>Offering inappropriate advice and concern</td>
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<td>Acting insensitively and without care</td>
<td>Acting insensitively and without care</td>
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<tr>
<td>Showing a negative attitude toward infertility or reproductive medicine</td>
<td>Showing a negative attitude toward infertility or reproductive medicine</td>
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<td>Being disappointed in not having children</td>
<td>Being disappointed in not having children</td>
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<td>Being criticized for not having children</td>
<td>Being criticized for not having children</td>
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<td>Mistakenly assuming that not having children was intentional</td>
<td>Mistakenly assuming that not having children was intentional</td>
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<td>Avoiding contact</td>
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**Providing encouragement at difficult times**

In addition to listening, understanding and sympathizing, providing encouragement was seen as effective. ‘Don’t worry. It’ll work out’; ‘It’ll work out so hang in there!’ and other positive encouragement about the certainty of a good result was reported. They also experienced pep talk from close friends and among women with similar experiences, who said things like ‘I’ve been in treatment for 10 years, but you’ve only been trying for 2 years! You must be all right [you will get pregnant].’

**Showing concern and interest**

Actions of concern such as showing interest in physical and emotional health were taken as positive. Specific instances included concern shown when treatment ended in miscarriage, or concern shown with regard to the physical effects of treatment. Examples included a father-in-law who had previously exerted pressure on a woman to have a child, but started to show concern for the woman’s feelings after a miscarriage.

**Not prying or interfering with the topic of children**

Most infertile women regarded others not prying or interfering with the topic of children as extremely beneficial. This was especially evident when it came to parents, parents-in-law and close relatives.

“I often hear that many people get asked ‘No baby yet?’ all the time by their mother-in-laws or other people, but at least I’m lucky and don’t get that” [age 29, 1 year 5 months, AIH].

**Respecting the women’s decision regarding fertility treatment and taking a wait-and-see attitude**

As will be described later, infertile women were affected by society’s prejudice concerning fertility treatment. Consequently, the attitude of important others toward treatment was important to them when deciding to start or continue treatment. One example given was of a parent not opposing IVF treatment and showing a supportive attitude. This was thought to be helpful.

“Maybe because my mother-in-law is still quite young, she understands, and knows there are treatments like [IVF]. She sees things on TV and says ‘Why don’t you try that?’ So, I’m really grateful” [age 43, 8 years, IVF–ET].

**Not being disappointed about the infertility**

This was experienced in interactions with mothers and mother-in-laws. For the women, it was reassuring when mothers/mother-in-laws did not show any disappointment about them not conceiving, and continued on normally in their daily lives.

**Providing useful information about fertility treatments**

Most cases were experienced in interactions with other women who had experienced or were experiencing infertility, and were a source of new knowledge and useful information about treatment and medical institutions for participants. Specific examples included information about options for infertile couples (treatment, adoption and folk therapies), introductions to good medical institutions and information that
Providing material support
Cases included other people preparing meals when the participant was not well after a miscarriage, buying supplements that were supposedly effective for infertility or bearing the costs of IVF treatment.

Negative social interactions
Prying with the topic of children
This was the category with the largest number of cases, and it was experienced not only with close others such as family and friends, but also with people who were not close, such as neighbors. Questions were not just limited to the general ‘Any children?’, ‘No children yet?’ type, but led on to more specific questions about reasons and preferences, such as ‘Why not?’, ‘Aren’t you going to have any?’ and ‘Do you want children or not?’ If the woman replied that she wanted children, but it was not happening, the next prying question would be, ‘Have you been to the hospital?’ Most of these interactions occurred with people who did not know the participant was undergoing fertility treatment.

Interfering where the topic of children are concerned
Following on from the prying questions about children, unwanted interference on pushing to have children was also not uncommon. ‘You need to lose weight,’ ‘XX shrine is really good,’ ‘[feeling the pressure points on the sole of the foot] this point here is knotted—that’s why you can’t conceive’ and other similar comments, especially from older women in the neighborhood, were reported. Other cases involved unsolicited advice about medical institutions, adoption, diets and folk remedies. When this interference was persistent and continued over a long period, it led some women to have very strong negative feelings.

Offering inappropriate advice and concern
Various cases were cited, including encouragement, introduction of hospitals and concern for physical and mental well-being. In all these social interactions, the other person intended to be supportive, but the interaction proved unsupportive to the infertile woman. One woman told of an experience whereby her mother-in-law, out of concern for her feelings, kept secret the pregnancy of a relative. However, this ended up making her feel even worse.

“[When I told her about the miscarriage] She just ignored it. You’d think that she would at least say something sympathetic, but she didn’t say anything. After that we began to drift apart” [age 36, 3 years, timing method].

Showing a negative attitude toward infertility or reproductive medicine
Some women were adversely affected by being at the receiving end of negative value judgments regarding infertility, fertility treatment and prejudice over male infertility and having only one child. Examples included, ‘You should avoid fertility treatment’, ‘you are not normal, IVF is not normal, so, you should not talk to people about, it can give a bad impression’. In one case, a woman had been told by her mother-in-law not to get treatment because it was unnatural and damaging, and she ending up having to hide the fact that she was getting treatment. As a result, she experienced the extra emotional burden of hiding the fact.

“She checked to make sure I wasn’t going to the hospital and [because I couldn’t tell the truth] I said ‘No, I wasn’t.’ I hate lying, but I don’t want to make her worry unnecessarily either” [age 40, 8 years, IVF–ET].

Being disappointed in not having children
Comments and value judgments about the loneliness of life without children, such as ‘You must be lonely without children’ were received negatively by participants, and made them want to react by saying “Just leave me alone”. Such comments were generally made by the elderly women. A woman who was considering terminating her treatment because of her age said:

“After I tell people I don’t have children, they invariably say, ‘Oh really? That must be lonely’. And that gets me thinking... is it better to have [a child]?” [age 43, 16 years, ICSI].

Being criticized for not having children
Infertile women were negatively affected when people criticized them for not being able to have children or not having children. For example, there were some women who suffered from mistaken judgments, such as a woman whose father-in-law, who lived in the same house, unjustly said, ‘There’s nothing wrong with the man. It’s the woman’s problem! So hurry and go to the hospital!’ Also, a woman who was blamed by her neighbors due to a misunderstanding, ‘This isn’t good. The population is shrinking and there are less and less children and it’s because of people like you’.

Acting insensitively and without care
This included cases in which other people talked about their own pregnancies and children. The participants recognized that the topic of children was inevitable when they were talking with people who had children. However, they did express a wish for other people to show at least a little consideration. One participant narrated her experience of telling a friend that she had miscarried after being pregnant through treatment, but got no reaction from her friend. Instead, the friend talked about her own joy at being pregnant. The relationship became estranged after this.

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Mistakenly assuming that not having children was intentional
Some people seemed to be envious when they found out that the participants did not have children. One woman described the feeling of while knowing that the other person did not mean any ill will, she found the words in a conversation with a former work colleague, difficult to take.

“I said I didn’t have children yet, and she said ‘But you’re lucky.’ I’m not working, so when she said, ‘You should be happy, you’ve got an easy life,’ it was quite rough. It’s not like I wanted this easy life” [age 29, 1 year 5 months, AIH].

Avoiding contact
Some cases fell under this category, and they had all been experienced in interactions with peer participants who had met in the outpatient department. Women undergoing fertility treatment often seek contact with peers, and get to know each other during treatment at the hospital. However, it seemed that the relationships often weakened and broke down once one of the women became pregnant. When the other person broke off contact because she was pregnant, the participants often felt shock, sadness and anger, and there was a tendency to dichotomize those whose treatment succeeded and who got pregnant and those who did not into ‘winners’ and ‘losers’.

“I guess [the other person] felt bad about getting pregnant first. So she thought it was better not to contact me. Then, I stopped contacting her. In IVF, there seems always to be winners and losers” [age 43, 8 years, IVF–ET].

Discussion
These results clarify the kinds of positive and negative social interactions infertile women experience in their networks.

Of the elicited categories of positive social interactions, listening closely to the distress experienced in infertility and treatment, showing understanding and sympathy towards the distress of infertility and treatment, providing encouragement at difficult times and showing concern and interest all serve a similar function to that of emotional support. These categories were evident in interactions with close people, such as family and friends, as well as other people with experience of infertility. Although the importance of formal support such as counseling for infertile patients have been indicated in the past, support from family members and friends has been less documented. It is probably because up until now, negative experiences of infertile women with such people were more documented. However, as described in previous studies, infertile women perceived friends and family members other than the husband as useful support resources (Callan and Hennessey, 1988; Boivin et al., 1999). Similarly, from our results, it is evident that others, particularly people in a close relationship with the infertile women, can be important emotional support resources for infertile women.

Showing understanding and sympathy toward the distress of infertility and treatment and providing encouragement at difficult times particularly stood out in the interactions with other women with experience in infertility. This confirms previous study findings, which show that interactions with similar others are helpful (Imeson and McMurray 1996; Bergart 2000). It seems that sharing similar experiences can help to form a sense of sympathy and reassure each other.

Many of the cases in the category of providing useful information about fertility treatments were applied again to interactions between women with experience of infertility. This is also one of the merits: people with similar experiences interacting together. However, what we cannot ignore is that they obtained information from other infertile women. That is, information that was not provided by medical doctors or the staff. These suggest that some women might not be able to obtain enough information from medical staff or could not understand the explanation given. Although it was not shown in Results section, many participants described that medical consultations are often too short for asking questions, and that doctors do not go into details unless patients ask. Also, in medical settings, the reasons for why treatment succeeded or failed in pregnancy are often unclear, and the time for medical examinations is often limited. Such factors may go some way to explaining the emergence of this category.

Providing material support is another important element of social support. However, this was only cited by a few participants. One reason may be that, compared with other conditions such as cancer, people coping with infertility have few material needs in everyday life. This, combined with the fact that this is a problem of the couple rather than that of the individual, the partner’s help plays a major role, leading to the unlikeliness of receiving material support from others. Nevertheless, fertility treatment can be a heavy economic burden, as one participant pointed out in her account of the support received through financial aid.

Offering inappropriate advice and concern included a whole variety of interactions. The problem here is that what other people said or did was well intentioned but fail to achieve their goal. This is probably because the interlocutor does not properly understand the needs of the patient. Studies in sociology show that actions intended to be supportive do not necessarily achieve their desired result (Antonacci and Depner, 1982; Rook and Pietromonaco, 1987). Sinn et al. (1984) suggest that, in order for support to be appropriate to the needs of the individual, it is not only the source of support that is important, but also other factors such as the amount of support, timing of support and function of support. Therefore, it is important to provide appropriate support in an appropriate way by ascertaining the needs of infertile women from such a perspective.

Acting insensitively and without care in this study referred to another person talking about her own pregnancy. On the other hand, hiding the fact of pregnancy was also taken to be an act lacking consideration. Previous literature described in length the fact that some infertile women are sensitive to other women getting pregnant. They become jealous or feel envy when they find out about another woman’s pregnancy (The Friends of Finnrage, 1994). It seems that this perception depends on particular situations, and that the subject of another’s pregnancy is not necessarily harmful to infertile women. However, it can be said that this topic needs to be treated with sufficient caution.
Prying with the topic of children and interfering where the topic of children are concerned were categories raised by many participants, who had experienced it with a whole range of members of their social network, from their own mothers and parents-in-law to neighbors. Judging from the fact that not prying or interfering with the topic of children was taken in a positive way, and that women expressed the wish that close family members would “leave [me] alone” and that neighbors would “stop asking about children as a substitute to saying hello”, this is probably a topic best avoided. The context behind these interactions involves social values that assume that a woman’s life is marriage–birth–childcare (Ohinata, 2000), especially the widespread value assumptions that ‘women only become true women when they bear a child’, ‘all women once married will have children’ and that ‘a life without children is a lonely life’ held by members of their social network. Moreover, it seems that these value assumptions also generate other negative interaction categories, such as showing a negative attitude toward infertility or reproductive medicine, people mistakenly assuming that not having children was intentional, being criticized for not having children and being disappointed in not having children. Members expressing such values toward infertile women could be putting a lot of pressure on them to have a baby, aggravating their depressive mood and/or reducing their support resources. And eventually, it may lead them to a state of social isolation, which is one of the infertile woman’s psychological responses (Imeson and McMurray, 1996).

According to a survey by Yamagata et al. (2003), although the percentage of ordinary people holding such values is decreasing, it is still not low. It is therefore necessary to get not only people around infertile women, but ordinary people as well to avoid imposing such values on others, to deepen their understanding of the health issue of infertility and to appreciate a diversified way of living for women.

Infertile women also reported encountering negative attitudes toward reproductive medicine from their mothers and/or parents-in-law. This is no doubt due to the fact that people in Japan tend to attach the value ‘natural’ to reproduction, due to the fact that there are still negative views toward reproductive medicine, and also due to the fact that many people do not have accurate information regarding reproductive medicine (Tokyo Women’s Foundation, 2000; Akizuki et al., 2001). Some women in this study had to go to the extent of hiding the fact that they were undergoing treatment because of the negative views of their parents-in-law. This kind of attitude from the people whose understanding is most crucial may lead to the loss of an important source of support. Respecting the women’s decision regarding fertility treatment and take a wait-and-see attitude was elicited as a positive social interaction category, showing that the attitude of respecting the decisions of the person involved and supporting those decisions and taking a wait-and-see attitude is important.

Another negative social interaction category elicited was avoiding contact. Similar experiences have been reported in relations with family, relatives and friends, especially those with children who do not have experience with infertility (Imeson and McMurray, 1996), but in this study, such experiences were limited to relations with those who had experienced infertility, and highlighted a disadvantage of interaction with peers.

In their study with IVF–ET patients, Mori et al. (1994) reported cases of patients harboring negative thoughts about interactions with peers, such as ‘invasion of privacy’ and ‘anxiety about being left behind’. In this study, there were women who were later avoided by their peers who got pregnant, and there were those who avoided contact on the grounds that, if they became pregnant first, they “would feel bad”. It seems that, although infertile women are all aiming at the same goal of pregnancy and birth, this factor can cause some strain in the relationships between them. It cannot be denied that if one woman conceives before the other, disclosing the fact may lead to temporary complications in the relationship between them. However, trying to avoid these complications by hiding the fact of pregnancy can result in even greater shock later. Telling the truth should make it possible to maintain a good relationship later on.

The implications of this study for formal support in medical or public settings are as follows. First, there is a need to convey positive ways of interacting with infertile women to the family, friends and local people who form the woman’s social network. Secondly, accurate information about reproductive medicine and the concept of reproductive health rights need to be diffused widely in society in order for negative attitudes toward reproductive medicine to diminish among the general public. Ordinary people’s views of fertility treatment range from thinking it provides a high chance of getting pregnant to seeing it as a severe physical risk (Tokyo Women’s Foundation, 2000). Also, as mentioned in Results section, an informant in this study stated that her mother-in-law believed that IVF–ET could cause defects in infants or an abnormal pregnancy. These suggest that it is difficult to claim that correct information is widely available in society, and it cannot be denied that this only serves to encourage negative attitudes toward reproductive medicine. Awareness reform on a societal scale is not easy to achieve, but it can be done little by little over a long period of time. One way is to further promote community lectures and seminars in order to provide accurate information about reproductive medicine and encourage positive social interactions with women with fertility problems.

The third point is that counseling services should be provided to both the infertile couple and their families in order to construct more supportive relations between them. This study showed that many infertile women experienced negative interactions with other family members and friends, perceiving the interactions as stressors. As written in ESHRE’s Guidelines (2001), support counseling should focus on working out new strategies of coping that might help in managing stressful situations. Therefore, it is necessary to discuss with these patients how they should manage stressful interactions with others. Also, our results suggested that there is a possibility that families are unaware of how to interact with infertile women. Recently, in Japan, some formal support systems have been constructed: a qualification of a counselor for infertile patients that was formed by a society, and infertility counseling centers
at the prefectoral level. However, whether these resources are accessible to family members of infertile couples is not clear. The reality is that families, with the exception of partners, very rarely accompany the patient to hospital appointments and consult such centers. Therefore, counseling should be extended beyond the couple to their families in medical and community settings.

This study examined the views of infertile women on positive and negative social interactions qualitatively. However, since the data are qualitative, there are limits to their representativeness. That is, we do not know the characteristics of the people with whom these interactions took place and the details of the experience, and therefore, no indications on tendencies can be stated. Quantitative research exploring the same issues is necessary in order to make more practical suggestions. In addition, in this study, the interactions of infertile women with their husbands and the medical staff were not evaluated. Therefore, positive and negative social interactions between infertile women and their husbands and the medical staff should be clarified in the near future.

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