

EMPIRICAL STUDIES

Support through patient internet-communities: Lived experience of Russian in vitro fertilization patients

OLGA G. ISUPOVA, PhD

Institute of Demography High School of Economics, Moscow, Russian Federation

Abstract

The article is concerned with the life experiences of infertile women going through infertility treatment and their need for social and psychological support, which they try to find in their immediate social environment. The Internet has become one place where everyone can find “people like oneself.” The best support is received from these people who are in the same life situation and are able and willing to share their lived experiences with each other. Communication via the Internet and the formation of a virtual community of patients has both positive and negative aspects, all of which are examined in the article. On the one hand, it creates a psychologically favorable atmosphere and might potentially increase the success rate of In-Vitro Fertilization (IVF) treatment. On the other, this leads to the seclusion of patients within the circle of “similar people” and sometimes to negative attitudes towards people outside the circle. The article is based on the author’s “netnography” research of a virtual community of Russian IVF¹ patients.

Key words: *Infertility, Internet-communities, shared experiences, patient self-support groups, reproductive technologies, social support*

(Accepted: 18 June 2011; Published 12 July 2011)

In Russia, more than 20,000 Assisted Reproductive Technologies (ART)² treatment cycles happen each year; the figure for 2008, for example (the most recent year for which data is available) was 31,127. Clinics are now located in all major cities throughout the country, though most are concentrated in Moscow and St. Petersburg. The average success rate in 2008 was 33.2% for classic IVF (RAHR, 2010). This is a reasonably high efficiency for this method.

There is no research indicating the incidence of infertility across Russia as a whole (Kuzmenko, 2008; RAHR, 2010). However, figures are available for some regions, varying from 8% to approximately 20% of the general population of women of reproductive age. Infertility was measured according to the World Health Organization (WHO) definition (Kuzmenko, 2008). According to Kuzmenko, male infertility, on its own or combined with female infertility, is also widespread and is encountered in 35% of couples seeking infertility treatment.

Psychological strain in infertile women and the importance of receiving social and psychological

support during IVF/Intra-Cytoplasmic Sperm Injection (ICSI)³ treatment have become increasingly pressing concerns and, because IVF is now well-established in Russia, success rates correspond to the average world level and infertility treatment is traditionally considered to be a “female” matter.

A number of studies (Abbey, Andrews, & Halman, 1991; Akizuki & Kai, 2008; Miall, 1986; Mindes, Ingram, Kliever, & James, 2003; Sandelowski & Jones, 1986) have indicated that infertility and fertility treatments are associated, both in women and men with deep and intense psychological strain that is, in many cases, exacerbated by adverse reactions on the part of those in their immediate social environment. Although these reactions are not always negative, it appears that those undergoing infertility treatment are likely to judge them hostile. Meanwhile, there is some evidence that positive social support tends to improve not only the psychological state of IVF patients but also the actual IVF outcome (review in Williams, Marsh, & Rasgon, 2007). Accordingly, many patients,

Correspondence: Olga G. Isupova, Institute of Demography Higher School of Economics, Pokrovsky bulvar 11, room D-212, 109028, Moscow, Russia. Tel: +7 495 7729590*2640. Fax: +7 (495) 772-95-90 *2458. Email: bolkab@yandex.ru

driven either by conscious decision or by their emotions, search for support not in their inner circle of friends and relatives but elsewhere. The longer the treatment takes, the more acute the need for support becomes.

Both qualitative and quantitative research has indicated that patients with infertility problems find the experience of having to communicate their infertility to their families and friends very challenging and often traumatizing (Abbey et al., 1991; Akizuki & Kai, 2008; Miall, 1986; Mindes et al., 2003; Sandelowski & Jones, 1986). This is so even if the resulting reactions are supportive. Since both positive and negative support are found to influence the psychological state of people undergoing treatment for various illnesses (Newsom, Rook, Nishishiba, Sorokin, & Mahan, 2005; Rook, 1998), all of the variants of infertility-specific social relations (support, appreciation, conflicts, and excessive demands) need to be studied.

According to Ingram, Betz, Mindes, Schmitt, and Smith (2001), there might be four major types of unsupportive social interactions in a situation of constant stress due to illness:

- Distancing, behavioral or emotional disengagement
- Bumbling, i.e., awkward uncomfortable intrusive behavior, inappropriately focused on trying to resolve the individual's problem
- Minimizing: attempts to force optimism on a person in a problematic stressful situation, to downplay the importance of his or her concerns
- Blaming, criticism, and fault-finding

Research (Awadallah, 2006; Bäckström, Wahn, & Ekström, 2010; White & Dorman, 2001) has demonstrated that when patients share their experiences this can form an important source of mutual support, which can in turn significantly improve the health and well-being of those involved. This is the case with real life patients' support groups and with those formed on the Internet (White & Dorman, 2001).

The literature on social support and infertility assesses both positive and negative support by people around the patients including self-help support groups. Each has an impact on their well-being. I will analyze the role of perceived and experienced positive and negative support as shared on the Internet; though the shared experience of negative support has, in my view, more interesting consequences and is given particular prominence in my study.

Aims and subject of the study

The main goal of this article is to investigate the lived experience of infertile women in Russia who use assisted reproductive technologies (ART), as revealed in forum discussions within their Internet community. Special emphasis is placed on the social and psychological support they receive from each other due to the sharing of similar experiences.

The Internet community—or the “virtual community,” as Howard Rheingold termed it in his 1993 book of that name—is a social network of individuals who interact through a specific media, namely the Internet. These people might have no geographical links, living in different places and in different states. What unites them is the possibility of pursuing mutual interests or goals with the help of the Web. Rheingold has emphasized the potential benefits of such communities for personal psychological well-being, providing a feeling of belonging for people who would otherwise not necessarily have it.

Virtual communities can only be considered communities in a “liberal” sense, as they are not based on any geographically united entity; however, they still possess boundaries between their members and non-members. The communities consist of social and professional groups and groups with similar interests or problems. The bond between members is not necessarily strong; nevertheless, they are often based on “sufficient human feeling” (Rheingold, 1993, p. 4), which allows for the formation of Web relationships and sometimes in due course, even personal ones.

Lipnack and Stamps (1997) and Mowshowitz (1997) investigated how virtual communities work across space, time, and organizational boundaries, and found that such communities are especially resilient in cases where there is a strong common purpose. Some negative aspects have also been identified; Mitch Parsell (2008) even suggests that Internet communities can be harmful because they lead to attitude polarization and increased prejudices amongst their members. They might also make it too easy for people with diseases to communicate about them and, in doing so, form an illusion of well-being in their un-treated states instead of getting properly treated at a medical institution. However, such negative traits might also be found in some “real” communities, if bonding between their members is strong enough, for example, religious sects or even small isolated villages.

My study takes into consideration the positive and negative aspects of such groups. Its specific objective consists of understanding the role such communities

might play in providing their members with social support by enabling them to share their experiences with people who have similar attitudes and are in similar situations.

Methodological and analytical approach

Elliott and Jankel-Elliott (2003, p. 215) outline ethnographic or quasi-ethnographic methods of research that can help to provide a “thick description” (in the sense elaborated by Glaser & Strauss, 1967), writing on the grounded theory of individuals’ lived experience. Later, the netnography method was developed (Kozinets, 2002), based on the study of online communication by members of various virtual communities for understanding their perceptions, imagery, attitudes, and emotions. According to Kozinets, the Internet provides special opportunities for participation in social groups and for asserting the social power of communities that are united around the achievement of particular lifestyle goals and characteristics. So, as Langer and Beckman (2005, p. 192) argue, netnography offers a “thick description” of people’s lifeworld. These and other authors (Pires, Stanton, & Cheek, 2003) stress that netnography is a particularly convenient method when there is a need to study communities that would be difficult to access by more traditional means because of the sensitive nature of the topics being researched. In addition, it would seem especially appropriate to use the Internet to research communities that would not exist without the Internet. Kozinets (2002) and Langer and Beckman (2005) also argue that this method is potentially less obtrusive than other methods of social investigation.

Netnography usually presupposes the following stages: *entrée*, when research issues are formulated and appropriate online “places” are identified; data collection, when the communications between members of a virtual community are observed and copied and the process of interpreting the possible meanings of virtual interactions starts; further analysis and interpretation, when the communicative acts of the participants are distinguished and the contextual “life” of the themes is grasped; then research ethics should be considered. The last stage is the member check, when some or all of the findings should be presented to the people who were studied, since their comments are to be considered when the final research conclusions are drawn.

Within the online community, different groups are often distinguished: “tourists,” who are attached both socially and thematically on a casual basis; “minglers,” whose attachment is mainly social; “devotees,” who are mainly, and strongly attracted by the community “theme”; and “insiders,” who are

heavily involved both socially and thematically (Kozinets, 2002, p. 64). The author of the present article agrees with the netnography concept that the last two categories are the most important data sources when studying an online community.

According to Kozinets, the basis of netnography is the observation of textual discourse. Accordingly, hermeneutic qualitative discourse analysis was the main method of data examination. Langer and Beckman (2005) argue that netnography is arguably closer to discourse analysis or qualitative content analysis of communication than it is to ethnography and that it ought to be positioned in between the other three.

Netnography is a particularly appropriate method for the study of IVF patients due to the sensitive nature of the topic. This would be hard to deal with in a formal or even informal interview but on the Internet, in a situation of quasi-anonymity, it is readily discussed.

The interactive forum of the site www.Probirka.ru was found to be the best source of information on the lived experiences shared by patients in their search for support. This site contains the largest thematic forum in Russia, with 20,885 registered users on 15 September 2010. It has existed since April 2003. At first it was organized by patients themselves for mutual support and information. In January 2008 it was bought by an IVF-related service agency but it remains a free and popular place of communication.

The ART patients from all Russian regions come together on www.Probirka.ru where they can exchange information, impressions and attitudes concerning the details of their treatment, and their interactions with particular doctors. In addition, there are many Russian-speaking women on the forum who were born in the USSR but now live in other countries and who are undergoing the same type of treatment in their countries of residence. These women can receive more practical information on similar sites in the countries where they now live, so for them, *Probirka* serves primarily as a place where emotions and “philosophy” concerning treatment can be exchanged.

My study was, in many respects, a classical netnography, though there were some peculiarities. At first I came to this Internet resource as a patient; I already had two IVF children and was considering having a third. For me, then, the main goal of engagement with the forum was personal, but consisted not of the desire to receive support in my path to having children but rather in “finding people like me.” This was partially caused by the fact that, despite being a mother, I felt in some respects very different to other mothers since I had come to

motherhood by a different route. My coming to the forum was perhaps prompted, at least in part, by a need for belonging. I found what I was looking for and very quickly became one of the site's activists, posting in forums and threads very intensely. When there are sufficient numbers of participants in a particular region, there is an established tradition of meeting each other physically. At first the participants are rather shy, but gradually find that such physical meetings with "people like them" provide a lot of benefits in terms of positive emotions. Eventually I, too, physically met up with many other women belonging to the community. These were mainly women based in Moscow, where I live, since it would be impossible to meet forum participants from all over Russia and other countries. I developed genuine friendships with some of the women.

Gradually I came to the decision that I did not want another child, so that ceased to be my motivation for involvement in the forum. I began to realize that my deep immersion in forum life had become both a reason and a motivator for studying it. My identity as a sociologist was never hidden from the other forum participants, and at some point I informed them that I intended to carry out research on the forum. This idea was met with enthusiasm, maybe because they felt they almost knew me "personally"—indeed, in some cases they really did know me personally—and so trusted me not to "misinterpret" their situations and motivations in a way that the mass media often do. My position as an active insider in the field would, of course, influence my interpretations but the researcher's subjectivity, when accounted for, is always a feature of qualitative research. As an insider, I also possessed deeper knowledge of and feeling for what was actually going on in this specific Internet community.

I took part in most of the discussions that I use for this article. However, I was not their most active participant. On the whole, about 50 participants with different nicknames took part in the forum threads I use here. About half of them were from Moscow and St. Petersburg, others were based in Tatarstan, Ukraine, the Czech Republic, and many provincial Russian cities (usually large cities, since both ART and the Internet are still very much urban phenomena in Russia).

For this article, the following spontaneous forum participants' discussions some of which were used took place over a long period of time (from 2005 to 2010):

- Whether to tell friends and relatives about one's infertility
- Whether friends of infertile people can become their "enemies"

- The image of the infertile in society as a whole including the views of different religions
- How psychologically strong—or just insensitive—the infertile become due to the experience of unsuccessful IVF attempts
- Envy of the fertile and how the infertile learn to deal with this in the course of their individual psychological evolution.⁴

These discussions were chosen because they provide information on the lived experiences of the participants as infertile women going through IVF treatment and trying to find people who can socially and psychologically support them, which was the focus of my research. Accordingly, posts that provided information on other themes were not analyzed here.

All of the informants are women: the Russian infertility-patient Internet is, for cultural reasons, seen as a "female space" since Russian society prescribes infertility as a woman's issue even in the case of male-only infertility in a couple.

Method of text analysis

The method I used was hermeneutic text analysis combined with elements of the ethnography of communication (EOC), a variation of discourse analysis that, unlike ethnography as such, is based on the assumptions that both language and culture are constitutive as well as constructive (Lindlof & Taylor, 2002). The EOC provides the possibility of using ethnographic methods while studying communication within a group (Cameron, 2001). Accordingly, communication between the participants of Internet discussions in my research was conceptualized as a continuous flow of information rather than a segmented exchange of messages. Since virtual web communities can be understood as one specific variation of "speech communities" (a term introduced by Philipsen, 1975), they might be expected to create their own speaking (writing) codes and norms, as well as constructing, during "conversation," shared social meanings of phenomena that have important meaning to them personally. Posting on the Internet can be considered a new form of communication, accordingly, a new form of "symbolic resources that are allocated and distributed in social situations according to distinctive culture patterns" (Philipsen, 1975, p. 21). This new form of communication is situated in between the oral and the written. It is written and even published in the sense that it is made public with the help of the Internet. However, it is also close to oral speech since it is generally not specifically edited or even well thought through, and the answers are expected

to come quite soon, and usually do, often from several different interlocutors.

My main aim in this analysis was to distinguish themes that were particularly important to the participants of this particular web community, without concentrating too much on the formal side of their discussion. The discussion as such was seen not as a group of separate messages but as a coherent flow in which meanings were constructed that were relevant and important to the group participants and to the topic of their discussion. Thus “local and continuous performances of cultural and moral matters” (Lindlof & Taylor, 2002, p. 45) were taking place. The topic of discussion was pre-established by one of the group members, but was then developed and diversified during “conversation,” through different communication events. Finally, an interpretation of the meanings that were under construction during the discussion is offered.

Ethical considerations

In Russia, there is no research ethics committee in this field. I provided the participants with information on my research (as soon as I realized myself that it was research and not just personal experience) partly by posting it on the forum and partly during real-life communication. No objections were expressed, only an interest in the results that I promised to share with them in the form of the published article.

Although “traditional” netnography recommends “open research,” with the researcher revealing his or her identity to the studied community members and enabling them subsequently to access the results, Langer and Beckman (2005) argue that the ethical approach to the Internet, especially when studying communities united by sensitive topics, should be more rigorous. Kozinets’s ethics recommendations are based on the understanding that the Internet, unlike conventional mass media, is not an exclusively public space, but neither can it be considered an absolutely private area; the extent to which any specific site, or even webpage, is considered public or private has to be decided case-by-case. Whether password usage is necessary to have access to a specific page is a key distinguishing feature. To Kozinets, Internet content should be considered undoubtedly public only if neither access to content nor the possibility of participating in the discussion require password usage. Langer and Beckman have a more relaxed approach to ethical considerations on the grounds that netnography is related to text analysis methods, where there is not such a strong requirement for informed consent on the part of the studied population. In addition, even within

traditional ethnography, covert research has not been entirely rejected, since it is thought to be appropriate when sensitive topics are studied. Lee (1993)

considers that there is rarely any justification for a researcher not revealing his or her identity or research aims, unless particularly sensitive topics were being studied and covert research was less likely to harm the participants because it was less obtrusive than open investigation.

Another feature of the Internet is that participants in discussions express themselves (quasi)anonymously, using virtual identities that provide them with what they feel is sufficient protection. Many people feel able to talk freely only on the Internet about topics that in some cases they would otherwise never mention at all. Accordingly, the Internet is the only space where one can find discussions on such topics (Solomon, 1996).

In light of the above, this research has been placed in between the ethical rules suggested by Kozinets, and the more relaxed procedures considered appropriate by Langer and Beckman. The content of the studied site (www.Probirka.ru) is a public space that anyone may access, though participation in the discussion requires password usage. The people taking part are not required to divulge any private information about their identities. Accordingly, this site, in the view of the author, should be considered closer to public than private space. The author’s own position as an insider in the studied community also has implications. On the one hand, her professional research interest was revealed to the potential informants (there were several occasions when the author placed a semi-structured questionnaire on the site and informed visitors about the ongoing research). On the other hand, the nature of site communication means that every day new participants are arriving on the site and old ones are leaving. This means that it would not be possible to inform everyone of the results because searching for those who had left the site would be impossible due to their virtual anonymity, and attempting to do so would in any case be intrusive since they did not want to reveal their real identities.

Moreover, while posting on this specific site, many participants consider what they are doing to be a public rather than a private act; they want their opinions to be available to any readers who happen to visit Probirka even occasionally. These are “intentionally public postings” according to Langer and Beckman (2005). Accordingly, the author decided that no actual member check was necessary, though her own insider position could be considered a partial member check. Participants’ anonymity was protected by not using their nicknames or pseudonyms,

but only the first letters of these nicknames. It should also be noted that these Russian participants themselves felt that anonymity was preserved precisely because they used nicknames, this fact was many times mentioned here and there in studied discussions.

Findings

Several informants stated that they were very satisfied with the emotional and sometimes even the practical and financial support of their friends and relatives, and that they never found themselves in a situation of distancing, “bumbling,” minimizing, or blaming.

M: Maybe I am just lucky, but I always received only positive support from my female friends. Some people told me that they were awaiting my daughter’s birth with more trembling feelings than when they were pregnant themselves.

L1: Everyone helped us by all the means they had—driving us in their car to the Moscow clinic, finding cheaper fertility drugs for us, lending us money, offering advice on choosing the best fertility clinic. Thanks a lot to everyone!

However, at least according to the forum discussions studied (and this finding corresponds with the work of other authors, i.e., Akizuki & Kai, 2008), examples of positive support are rarer than those of negative support. This might be partly explained by the fact that due to increased sensitivity resulting from the stress of infertility, patients’ perceptions of others’ attitudes could be rather intense and exaggerated.

In any case, the majority of participants in the forum feel uncomfortable about the reactions of people around them. As Loftus (2006) states, in the case of negative support many infertile people are likely to stop or suspend relationships that are associated with psychologically painful attitudes in relation to their health strategy or with unwelcome advice. My study supports this finding.

M: The most unpleasant thing for me was to hear from my closest friend something like: “maybe bearing children is not your predestination.” I still cannot speak to her, right up to the present day.

Kr: I am very reserved by nature, I do not like all these questions. So gradually my meetings with my best friend became less frequent and then stopped completely.

Another issue concerns the fact that some relationships are not easy or even possible to break or suspend: namely, those with husbands/partners involved in the shared infertility/treatment process or these with close relatives with whom they live or who help with the cost of treatment.

Z: To what extent it is possible to hide infertility and its treatment from your parents, if you live together in the same apartment?

Kr: Only the closest ones know about my IVF—my husband (naturally) and my parents (they help us financially).

Only for those who really are both financially and psychologically independent, which in the Russian case usually also means they are older, things are easier and they can really decide themselves about “whom to tell.”

K: I am married for the second time, I am a mature person, my husband is also not a young boy, so we are independent from all our relatives both financially and emotionally. So they have no say in the issue of our infertility treatment.

Those who cannot avoid “letting others know,” although they would prefer not to, have to elaborate more complicated strategies in the event that their “significant others” are not sufficiently, or even at all, psychologically supportive. For example, they can “change the direction of blaming,” and, instead of suffering because they are blamed by others for their infertility, shift this blame to other people for not being supportive enough. They can even somehow force them to become supportive.

B: My husband’s father was asking me about children at every meeting—so all meetings with the family ended up making me depressed. Finally my husband had a tough conversation with his father and somehow persuaded him not to ask me about this anymore.

It could also be argued that in Russia broader social attitudes to IVF are more hostile than elsewhere or at least more openly hostile. This includes the opinions of neighbors and acquaintances as well as a large part of the mass media and, on occasion, even of medical officials who have been known to openly express hostile views about IVF. For example, Alexander Baranov, the Major Pediatrician of the Russian Federation, claimed publicly several times during the year

2009 that 75% of IVF children have birth defects and are biologically inadequate and so the state ought not to spend money on ART. He made this point, for example, during a round-table conference at The House of Journalists in Moscow on 13 November 2009 (<http://www.probirka.org/dealing/krugliystol.html>, accessed 20 April 2011). With the overall situation not being welcoming to artificial reproduction, it is not surprising that some relatives are very hostile to the idea that their grandchildren will be IVF-conceived, expecting them inevitably to be “inadequate.”

L: If my in-laws learn that my child is IVF-conceived, it would be easier for me to commit suicide, honestly. All the negative opinions about this treatment will be collected and presented to me. They are simply afraid of all new methods. Also, they believe it is not natural. They will be afraid that something will be wrong with the child; that he must have birth defects.

Z: I have a colleague at work, she believes that all IVF children later have infertility problems themselves and will not be able to have children of their own.

T: Even I, when this was not yet an issue for me, had the opinion that IVF was something artificial, unnatural, though I believe that I am, on the whole, a sufficiently modern and reasonable person.

When they spoke about the attitudes of people with whom they did not have particularly close relationships, informants suggested that the negative view of costly ART treatment was often influenced by jealousy; they believed that those who could afford such treatments must be too rich and maybe had few “real problems” in life.

Lu: My female friend said that if you cannot, than there is no need to do it, and if you disturb God by your stubbornness, than you will give birth to a child, but it might be a freak or a maniacal killer . . . meanwhile she herself has a child, and she always stresses that I am free to care for myself and do not understand my good fortune, while children are such a strain, such a responsibility.

O2: Infertility is our pain, and everyone has their own pain. Some do not have housing, others do not have husbands, others lack money . . . So they understand only their own problem and not ours, it is natural.

On some occasions, patients feel such stigmatization that they are forced to choose a childless circle of friends, and they feel that “normal” people avoid communicating with them.

Frz: I have noticed that I started more often to meet unmarried or childless female friends. I feel uncomfortable with people whose situation is “normal” and I avoid them.

Russian norms concerning the social obligations of marriage and motherhood for a woman are relaxing to some extent, but only in Moscow and St. Petersburg and are still relevant elsewhere.

Ah: In society’s “eyes,” there are “adequate” and “inadequate” people. If you are about 30 years or older, you’re adequate only if you have a husband, a child, maybe also your own housing.—All women who do not fit this scheme are “inadequate.”

Of course, in view of such stigmatization, the majority decide not to tell anyone either about the fact of their infertility or its treatment. This is in line with the overall character of traditional Russian society, which is rather closed regarding the discussion of any sensitive matters of personal relevance.

A: Around me, no one knows, except for my husband. My parents live far away, and I do not want to bother them. And at work, on all the occasions when I go for treatment, I lie. I have become used to this already.

Those who do tell others are either “westerners” in terms of their values (this often corresponds to the tactful behavior of people around them) or, more often, simply cannot keep secrets due to the peculiarities of their characters. One reason for talking about their situation is a desire to provide other infertile people with information about treatment that they would not receive otherwise.

Chv: I tell everyone. I am an extreme extrovert and cannot live through my problem alone, while my husband does not like to speak—so I need other people I can confess to.

Vs: I do not hide this, because other people might need the help and information available to me due to my experience.

In many cases, informants need to carefully choose the people to whom they reveal their situation since the need for positive support and the necessity to avoid negative reactions are very difficult

to balance. It is also very difficult to predict who will react in the preferred way.

Yu: I sit down and think about my friends and relatives, what I can tell to whom. My sisters know about IVF on the whole, but for some reason I feel it would be better to tell them [about my situation] only when I have already got a positive result.

A: In my parents' family it was not usual to confess anything to anyone. So I do not tell them anything. I have told my husband something, but not a lot. Often, I prefer to confess to absolute strangers if I know that I am never going to meet them again.

The typical "telling" evolutionary process, with the individual trying to ensure that psychological comfort is the highest possible, consists of being very open and extrovert in the beginning, and then gradually becoming more and more reserved, making constant attempts "not to tell" in order to preserve her "inner self" from hurt due to the intense interest of her circle in the fact that she has had an unsuccessful IVF attempt.

Sl: The first time, almost everyone knew about our IVF attempt, the second time—a couple of people, and the last time—no one but ourselves.

On the other hand, some patients have no choice but to reveal information—to their workmates or superiors at work because they need to take time off during work days to visit doctors or the bank since they have to ask for a loan to have treatment. This can become very frustrating for many if they would personally prefer not to tell.

Ggr: We had to ask for a loan from a bank to pay for IVF treatment, so we had to continuously explain everything both to acquaintances and to absolutely unknown people. So all [my] shyness or introversion had to disappear momentarily.

Ll: Everyone knows about my IVF, at least at work, since they regularly have to allow me to go to another city to have treatment.

Going through infertility and its treatment is generally not easy and the psychological aspects of this are by no means the least important. As a consequence of the negative attitudes stated above, many informants at some point start blaming themselves for their infertility or feel persuaded to give up and get depressed.

Mml: Maybe this is destiny or fate? Both of us, my husband and myself, are carriers of one and the same genetic mutation, and our child has a 25% probability of being born ill . . . So we need IVF+PGD,⁵ which is very expensive. How could it happen that we found and loved each other, being of different nationalities and born in opposite corners of such a large country as Russia?

Nevertheless, some are able to find ways to conquer this kind of mood even in the absence of proper support, either by asking professional psychologists for help or by helping themselves in their own ways to change their attitude.

L: If it is impossible to change the situation, it is possible to change your attitude towards it.

Other ways include trying to transform the problem from something that seems huge and overwhelming into a sequence of small and easy tasks, and forming a stronger and more indifferent attitude to what others say and think about them, distancing themselves, and paying no attention to what others say.

Irsk: I would divide the problems into parts. For example, if you want to break the broomstick with your hands, it is a very difficult task. But if you first untie it and then break every thin stick separately, the problem becomes elementary. The "what-to-do" ought to be more important than the "who-is-to-blame."

B-p: They cannot bother me in any way. If someone tells me that I am worse than they are because I do not have fallopian tubes or ovaries—I would easily find other things in which I am much better than anyone else.

There is also the option of diverting one's attention to other tasks, the more difficult and practical the better, since this allows people to put all their efforts and attention into them, leaving no place for grief or depression.

EK: Of course it is possible and necessary to sit down and think, but there are dead-locked thoughts—such as the idea of the infinity of the Universe, for example. You had better make a practical plan for yourself, with partial tasks, what's first, what's next, how many times, how many years . . . this at least is a way which leads somewhere.

A good “way out” consists of re-interpreting the “signs sent by fate” in a more favorable light.

El: But you have wonderful odds! Two-thirds of your embryos are going to be healthy and implantable. Your glass is not one-third empty, it is two-thirds full!

All these “lay psychological techniques” do not contradict the religious beliefs some patients have since, in their view, this does not mean you cannot take an active role in dealing with your own concerns; also, leading a difficult life might mean that you are especially loved by God.

Zia: Everything is God’s will. But God gives things only to those who try to get them themselves. And God gives trials only to those beloved to Him.

However, precisely at this point we can see that personal decision is the most important: if someone chooses not to treat her infertility but to accept it, absolutely different views and ideas, albeit from the same religious system, might be mobilized.

Ch: A human being can choose either to change herself and accept her own weakness, or to be stubborn, thus increasing her sorrows. All physical illnesses are connected to our souls. We ought to treat the soul first, refusing ourselves to intense bodily wishes such as desperately seeking children. Thank God, I do not have the money for IVF treatment. And even if I had the money, I would better spend it traveling to the holy places.

In some cases the very process of the formation of personal attitudes and will is demonstrated to us in detail. This often happens at the rock bottom point of continuous failures, against a background of depression and without receiving any psychological support from anyone. Precisely at this time a person often has no other option than to “sit down and think,” re-evaluating the different options remaining to her.

Sn: After the next IVF failure I felt absolutely desperate. My husband was depressed too. I did not know whether it was worthwhile to continue [with IVF] attempts. So during a sleepless night, thinking about my gloomy fate, a thought came into my head. The thought was that I do not have any more physical or psychological energy to continue . . . but, then, it would be much, much worse

to stop and refuse myself the possibility of motherhood. The conclusion is—that we are continuing our way to our precious goal . . . even though the pace is so slow.

Frz: If my situation had been different, I would be another person myself. I could not have passed through all these periods of deep thinking about my life and values, trying to understand all these reasons and consequences and the associations between them.

Some “emotional evolution” is apparent, which depends on the “length of the journey to the child.”

Yavl: There is an evolution in the infertile woman’s feelings. Everyone has almost the same scenario, only the shorter your way to the child in the IVF “world,” the less reflection there is on “why and how.” Like, yesterday I was jealous, and now you can be jealous of me! And the theme is closed. But those who are here for a long time weep and cry due to envy, despair, and self-pity.

It is difficult to make this journey alone; yet the husband is often not deeply involved in the process of getting IVF treatment; and if he does take part, he is not always sufficiently supportive.

Nst: Sometimes I need to tell everything to someone, to cry. My husband is not going to support me anyway, maybe this is because men are such senseless creatures on the whole.

Accordingly, the majority of patients need positive support and have to search for it somewhere. Most often they find it precisely in the Internet forum, where they can opt either to remain permanently anonymous or, more often, eventually meet other participants in person. Informants affirm that for people in their situation, forums are the best option for receiving support, since the other participants are just like them, in situations similar to their own. Even a professional psychologist’s help is often “graded” lower.

Mrk: Now I found my salvation in the Probirka forum. It becomes much easier when you learn that there are many other people like you, and that you can express your feelings and there are people who can understand. Although I am a professional psychologist myself, I would not be able to overcome such a serious problem on my own.

Forums of IVF patients give them an invaluable feeling of belonging and solidarity, which really empowers them, making them feel stronger and better prepared for facing the continuing hardship of infertility and its treatment. Accordingly, my understanding is that the most supportive aspect of the forum is the very fact of sharing experiences with people in a similar life situation and with whom they form a virtual community.

A number of superstitious and sometimes amusing cultural practices and beliefs have been generated by the group of patients studied in this research, which they have found psychologically helpful. These include sitting in a chair that a pregnant woman has just vacated, and eating “pregnancy sweets” bought by a woman who had recently become pregnant and that she offered to friends who were still trying to get pregnant. Then, if they do get pregnant, many women prefer not to tell anyone apart from the people closest to them before the pregnancy is at least 3–4 months in gestation in case this puts a jinx on them.

B-p: At my work place I took a chair formerly occupied by two women who both in turn became pregnant. I hope this will help.

Kl: I told such a large number of friends and colleagues about my first pregnancy. And then I had a miscarriage. So who put an evil eye on me?

Many infertile women become somewhat hostile to “others” who are “not like us,” and have different attitudes to “our” pregnancies and those of “other” women. The former are welcomed as long awaited, consciously planned, and struggled for pregnancies, while the latter often generate a feeling of envy, personal offence, and spite on the grounds that “Someone in heaven gives children to those who do not really deserve them.” It is therefore not surprising that “others” are often afraid to reveal their pregnancies to infertile friends. Yet this is even more insulting to the infertile woman.

Uh: My acquaintances always hide their pregnancies from me, not only thinking that I am going to be jealous, but also that I might put an evil eye on them, as they believe infertile women are witches!

Often, “other” women’s pregnancies are perceived as too “easily achieved,” and the women are accused of everything imaginable: they are bad mothers, whores, have had many abortions and sexually transmitted diseases, but are able to get pregnant anyway due to their “diabolical good health.” We can

see in this the reverse of the stigmatization that is often directed at them by society at large. They also use identical arguments.

OK: I felt jealous when I saw prams and when I saw other women’s pregnant tummies on the street, and I wondered why alcoholics and the homeless could easily get pregnant and I couldn’t.

Summary of findings

A comprehensive understanding of the findings might be summarized as follows. All of the responses stated by Ingram (Ingram et al., 2001)—distancing, bumbling, minimizing, and blaming—were experienced by some of the Russian IVF patients, as mentioned in their forum postings. However, not all of the women experienced all of these responses and some claimed that they have never encountered any of them. Patients most often stated that others perceived their situation negatively, but in some cases this might be due to the fact that their heightened sensitivity, caused by the stress of IVF treatment, led them to exaggerate the actions and words of people around them. The majority of female patients reacted by suspending their relationships with people whose attitudes to their situation were experienced as especially painful. Some women, however, were unable to do this because they were dependent on these people, psychologically, financially, or both. In this case they formed protective discursive strategies and “changed the direction of blaming,” shifting this blame back on those people who they perceived to be blaming them for their infertility. Hence, a rather aggressive attitude developed; the feeling of belonging and becoming empowered members of this virtual community was to some extent based on “excluding” others.

Patients felt compelled to form discursive strategies to protect themselves and their children not only from the reactions of their friends and relatives but also from society at large, as expressed in the Russian media. Most often these were strategies of hiding but in some cases they were open expressions of opposition to hostile attitudes. The first of these two strategies corresponds best to Russian society’s norms concerning behavior related to sensitive topics in general. The second is the characteristic mainly of the activists in this virtual community, who want to provide other infertile women with information about treatment that they would not receive otherwise. Both strategies undergo an

“evolutionary” process while women go through the various stages of their IVF life experiences.

Women share with other forum participants the difficulties they encounter in their relationships with “real-life” female friends who are in different life situations (they do not suffer infertility, they may have children, they may not want children, they may have insufficient money, etc.). They express hope that there will be more mutual understanding between them and their virtual/real friends who are also IVF-patients because they have similar life experiences.

Increased sensitivity to other people’s reactions is often interwoven with the formation of a discursive strategy of self-blame or self-stigmatization. However, the participants in several discussions found ways of transforming this self-blame into more assertive attitudes without anyone else’s help (dividing the difficult process of infertility treatment into several “small and easy” tasks, or reducing their obsession with infertility by becoming involved in other activities). Religious and other beliefs are brought to bear on the resolution of their infertility and are used to support the decision they have already made as to whether to continue trying to get pregnant.

Several participants claim that the forum is their main source of psychological support, and that it helps even more than professional psychologists because it provides them with empowering feelings of belonging and solidarity.

Discussion

Perceptions about infertility and the attitudes of people close to the patients are similar in Russia to those in many other countries. Accordingly, infertile women in Russia going through IVF, according to their own accounts, receive spontaneous social support (both negative and positive) from their relatives. However, the attitudes of society at large could be seen as somewhat more hostile in Russia than elsewhere. In this situation, the role of informal patient communities based on Internet forums is very important as a source of relief and consolation to their members. The social and psychological support these forums provide comes mainly from the possibility of sharing individual experiences of infertility and its treatment with empathetic people who are in a similar situation. Nevertheless, the role of such communities can be negative as well as positive. As we saw earlier, Loftus (2006) and Parsell (2008) felt that Internet communities could encourage attitude polarization and increased prejudices amongst members, while Parsell suggested that they might also create an illusion of well-being that

resulted in their members not seeking necessary medical treatment. The former was sometimes the case with Probirka members but not the latter. Probirka patients do not avoid doctors and treatment but use the forum as a source of additional information and advice on matters such as which doctor to choose; the forum also provides them with psychological support that is not often given by doctors anyway. In Russia this role might be more important than it is in many other countries, since receiving professional psychological help is still not common.

Internet communities relating to infertility are especially helpful for people who are inclined to continue treatment until a positive result is achieved. If they begin to hesitate, the community might play a substantial role in encouraging them to continue IVF attempts. However, the data suggests that people with a strong inclination to stop treatment are likely to be immune to this influence, and they can always find another Internet community to support their attitudes (for example, religious forums).

Conclusion

The diversity of Internet communities makes a significant difference in the continuum of infertility decision making since such decisions, whatever their direction, are now being made on the basis of larger informational resources than they were before. However, the most important thing about the Internet in relation to infertility is that it provides a place of virtual meetings for “people like you,” which makes this decision-making process more comfortable. Now, regardless of what decision one makes, it is possible to find people like oneself who offer support on the basis of a shared understanding of common problems and experiences. In the past one was forced to protect one’s decision, with all its consequences, by oneself, and often in hostile surroundings. For those who are not active Internet users, this is probably still the case.

As was hypothesized in the beginning of this article, the Internet forum, organized by patients themselves in order to enable infertile women to communicate with each other and provide each other with information, has become an important source of patient education and mutual support. That sharing experiences provides support accords with the findings of other authors (Awadallah, 2006; Bäcktröm et al., 2010; White & Dorman, 2001).

Regarding those patients who are determined to succeed in getting pregnant via IVF, it is possible to hypothesize that final IVF success rates among them (the percentage of baby-take-home rate after all of

the attempts made by each person) are higher than among those who are deprived of this kind of support. This is mainly because they carry on using IVF for longer, having more attempts on average. Furthermore, despite the fact that they are likely to spend more money and time on IVF treatment than those who give up without achieving pregnancy, their journey to this result is less troubled and, hence, their well-being increased.

Acknowledgements

I thank all participants in the discussions of the forum Probirka.ru, who had inspired me with their views and ideas on infertility, as well as with their personal experiences they shared in the Internet. I am also grateful to all reviewers of International Journal of Qualitative Studies on Health and Well-being, who's comments were extremely useful to deepen my thinking on the topic of personal experiences of infertility and possible sources of support for infertile women.

Conflict of interest and funding

The author has not received any funding or benefits from industry to conduct this study.

Notes

1. IVF, or in-vitro fertilization is a medical technique allowing an otherwise infertile couple to achieve conception with the help of manipulations that consist of removing mature oocyte(s) from the woman's ova and putting them into a Petri dish with a special biological nutritious medium, where the sperm sample can "naturally" fertilize them; several days later, the embryos are transferred into the woman's womb where pregnancy might later develop.
2. ART, assisted reproductive technologies is a term relating to a range of reproductive techniques, all of which presuppose stimulation of a woman's fertility with hormones and/or technical manipulations with semen and ova taken out of male and female bodies in cases where the "traditional" way of conceiving a child is for some reason impossible or fails to work. In all cases, the resulting pregnancy, if there is one, continues to develop in the female body until the birth of the child.
3. ICSI, intra-cytoplasmic sperm injection, is a technique involving the taking of one chosen sperm with a very small needle and then, under microscope supervision, inserting it straight into the oocyte (which was taken out of the female ovary in the same way as during classic IVF). Accordingly, ICSI is a technique additional to IVF and is performed in the case of severe male factor infertility (irrespective of whether there is also female infertility). If the sperm is "good enough" (i.e., contains a sufficient number of healthy spermatozoa), classic IVF is performed; that is, the oocyte is simply put in the sperm sample so that the spermatozoa can "decide themselves" which of them is going to fertilize the egg.
4. See <http://probirka.org/forum/viewtopic.php?f=92&t=20592>, <http://probirka.org/forum/viewtopic.php?f=92&t=14118>,

<http://www.probirka.org/forum/viewtopic.php?f=92&t=281>,
<http://www.probirka.org/forum/viewtopic.php?f=92&t=5342>,
<http://www.probirka.org/forum/viewtopic.php?f=92&t=8127>,
<http://www.probirka.org/forum/viewtopic.php?f=92&t=11243>,
<http://www.probirka.org/forum/viewtopic.php?f=92&t=4494>,
<http://www.probirka.org/forum/viewtopic.php?f=92&t=11285>,
<http://www.probirka.org/forum/viewtopic.php?f=92&t=5738>,
<http://www.probirka.org/forum/viewtopic.php?f=92&t=17983>,
<http://www.probirka.org/forum/viewtopic.php?f=92&t=11236>
all assessed 30 April 2010.

5. PGD, preimplantation genetic diagnosis is a test carried out on a 5- to 6-day-old embryo before putting it into the womb in order to diagnose whether it has serious genetic defects. Only the healthy embryos are then put in the womb in order to avoid producing children with defects that would cause their premature death anyway. It is performed only when absolutely necessary, usually when a couple has already given birth to a sick child.

References

- Abbey, A., Andrews, F. M., & Halman, L. J. (1991). The importance of social relationships for infertile couples' well-being. In A. L. Stanton, & C. Dunkel-Schetter (Eds.), *Infertility: Perspectives from stress and coping research* (pp. 61–86). New York, NY: Plenum Press.
- Akizuki, Y., & Kai, I. (2008). Infertile Japanese women's perception of positive and negative social interactions within their social network. *Human Reproduction*, 23, 2737–2743.
- Awadallah, M. S. (2006). Support for cancer patients: The Bahrain experience. *Eastern Mediterranean Health Journal*, 12(5), 695.
- Bäckström, C. A., Wahn, E. I. H., & Ekström, A. C. (2010). Two sides of breastfeeding support: Experiences of women and midwives. *International Breastfeeding Journal*, 5(20). Retrieved June 1, 2011 from <http://www.internationalbreastfeedingjournal.com/content/5/1/20>
- Cameron, D. (Ed.) (2001). Situations and events; the ethnography of speaking. In *Working with spoken discourse* (pp. 53–67). London: Sage.
- Elliott, R., & Jankel-Elliott, N. (2003). Using ethnography in strategic consumer research. *Qualitative Market Research*, 6(4), 215–223.
- Glaser, B. G., & Strauss, A. (1967). *Discovery of grounded theory. Strategies for qualitative research*. Mill Valley, CA: Sociology Press.
- Ingram, K. M., Betz, N. E., Mindes, E. J., Schmitt, M. M., & Smith, N. G. (2001). Unsupportive responses from others concerning a stressful life event: Development of the Unsupportive Social Interactions Inventory. *Journal of Social and Clinical Psychology*, 20, 174–208.
- Kozinets, R. V. (2002). The field behind the screen: Using netnography for marketing research in online communities. *Journal of Marketing Research*, 39(February), 61–72.
- Kuzmenko, E. T. (2008). *Cliniko-epidemiologicheskie aspekty zhenskogo besplodiya na primere Irkutskoi oblasti* [Clinical and epidemiological aspects of female infertility, Irkutsk region example]. Unpublished thesis for the degree of Candidate of Medical Science, Russian Academy of Medical Sciences at Siberia.
- Langer, R., & Beckman, S. C. (2005). Sensitive research topics: Netnography revisited. *Qualitative Market Research: An International Journal*, 8, 189–203.
- Lee, R. M. (1993). *Doing research on sensitive topics*. London: Sage.
- Lindlof, T. R., & Taylor, B. C. (2002). *Qualitative communication research methods* (2nd ed). London: Sage.

- Lipnack, J., & Stamps, J. (1997). *Virtual teams: Reaching across space, time, and organizations with technology*. New York, NY: John Wiley & Sons.
- Loftus, J. (2006, August). *Reconstructing relationships: How infertile women cope with negative social support*. Paper presented at the annual meeting of the American Sociological Association, Montreal Convention Center, Montreal, Quebec, Canada.
- Miall, C. E. (1986). The stigma of involuntary childlessness. *Social Problems*, 33, 268–282.
- Mindes, E. J., Ingram, K. M., Kliewer, W., & James, C. A. (2003). Longitudinal analyses of the relationship between unsupportive social interactions and psychological adjustment among women with fertility problems. *Social Science and Medicine*, 56, 2165–2180.
- Mowshowitz, A. (1997). Virtual organization. *Communications of the ACM*, 40(9), 30–37.
- Newsom, T., Rook, K. S., Nishishiba, M., Sorkin, D. H., & Mahan, T. L. (2005). Understanding the relative importance of positive and negative social exchanges: Examining specific domains and appraisals. *Journal of Gerontology, Series B: Psychological Sciences & Social Sciences*, 60, 304–312.
- Parsell, M. (2008). Pernicious virtual communities: Identity, polarization and the Web 2.0. *Ethics and Information Technology*, 10(1), 41–56.
- Philipsen, G. (1975). Speaking “like a man” in Teamsterville: Culture patterns of role enactment in an urban neighborhood. *Quarterly Journal of Speech*, 61, 13–22.
- Pires, G., Stanton, J., & Check, B. (2003). Identifying and reaching an ethnic market: Methodological issues. *Qualitative Market Research*, 6(4), 224–235.
- RAHR (Russian Association for Human Reproduction). (2010). *The year 2008-th report*. Saint-Petersburg: RAHR.
- Rheingold, H. (1993). *The virtual community: Homesteading on the electronic frontier*. Reading, MA: Addison-Wesley Publishers.
- Rook, K. S. (1998). Emotional health and positive versus negative sides of personal relationships: Through a glass darkly? In B. H. Spitzberg, & W. R. Cupach (Eds.), *The dark side of close relationships* (pp. 369–393). Mahwah, NJ: Lawrence and Erlbaum Associates.
- Sandelowski, M., & Jones, L. C. (1986). Social exchanges of infertile women. *Issues in Mental Health and Nursing*, 8, 173–189.
- Solomon, M. B. (1996). Targeting trendsetters. *Marketing Research Forum*, 8(2), 9–11.
- White, M., & Dorman, S. M. (2001). Receiving social support online: Implications for health education. *Health Education Research*, 16(6), 693–707.
- Williams, K. E., Marsh, W. K., & Rasgon, N. L. (2007). Mood disorders and fertility in women: A critical review of literature and implications for future research. *Human Reproduction Update*, 13, 607–616.