Gender aspects of male perception and attitudes to own infertility, its treatment and ART usage in Russia

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The present paper is concerned with the life experiences of infertile men and their female partners in what concerns going through male infertility treatment. The Internet has become one place where everyone can find "people like oneself." Many people find the best support they can receive is from these people who are in the same life situation and are able and willing to share their lived experiences with each other. However, it is not at all the case with infertile men in Russia. They almost never share their experiences concerning stated health condition with other men in similar life situation in the web. On the other hand, their female partners do so often, and unite on the special sites in order to discuss the problems of their men. 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 by one of the authors of present paper (Isupova, 2011). 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. As well as a referenced article, current paper is based on the authors "netnography" research of a virtual community of Russian IVF¹ patients.

In Russia, 40961 Assisted Reproductive Technologies $(ART)^2$ treatment cycles happened in the year 2009. It is the most recent year for which the data is available. 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 2009 was 33.0% for classic IVF (<u>RAHR, 2011</u>). This is a reasonably high efficiency for this method.

There is no research on the incidence of infertility across Russia as a whole (Kuzmenko, <u>2008</u>; <u>RAHR</u>, <u>2010</u>). 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, <u>2008</u>). 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 (this is not representative survey data but the result of studying only couples referring to reproductive clinics to seek treatment).

Contemporary fertility in almost all countries of the world is being formed with, though yet moderate, help of ART, which, in the best case, can contribute up to 4% of yearly national fertility. Though social attitudes to these methods are ambiguous, in the vast majority of the countries these technologies are being used for more than 25 years already. One of the reasons for their relative popularity consists in the states willingness to use all possible resources to increase fertility in ageing countries and improve population health.

Recent research demonstrates differences in male and female reproductive behavior, especially in what concerns timing of parenthood and desired number of children (for example,

¹ IVF, in-vitro fertilization: a medical technique presupposing 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. Later the embryos are transferred into the woman's womb where pregnancy can later develop.

² ART, assisted reproductive technologies: 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 usual way of conceiving a child is for some reason impossible.

Lampic et al., 2006). Births are being postponed, age at motherhood and at fatherhood grows. Potentially, these might be associated with worse reproductive health in both women and men (Lampic et al., 2006). Medical data demonstrates possible gradual decline of sperm quality from generation to generation ("spermatozoid crisis", Skakkebaek et al., 2006). On the other hand, men's desire to have children is often higher than women's, at least in Russia. According to the Russian Committee of Statistics "Semya I Rozhdaemost" survey (2010), both desired (2,38 versus 2,28) and expected (1,90 versus 1,72) number of children is higher in men than in women. Men want having 2 children 10% more often, than women, and three times as often as women they want to have three children.

Although ART appeared in 1978 as a specific means to resolve female reproductive problems, soon they started to be applied in the case of male reproductive health being impaired, too. On the other hand, they also created the possibility for healthy males to become sperm donors. Since male reproductive problems are highly relevant, Russian ART clinics suggest wide spectrum of options to men with different reproductive status (from becoming donors to using cryo-conservation of their own healthy sperm at younger age before any problems appear).

According to current registration of couples recurring to fertility treatment in several Moscow fertility clinics in 2010, men very seldom come there themselves, usually the state of their reproductive health is becoming evident only when the couple seeks treatment and only after a woman is totally scanned. A woman most often is being considered apriori "guilty id a couple wants to start a family but cannot. This might be associated with archaic cultural norm which is still widely spread by now: that infertility is associated with a woman only ("barren woman"= "barren land"), while a man is associated with his sexual function, and, if the latter is normal, he 'cannot be' infertile. And, if there are problems with his sexual function, it is a very stigmatizing state, which should be hidden from everyone by any means (Pfeffer, 1993).

Number of accepted sperm donors is not higher than 30-50 persons in Moscow reproductive clinics, usually, from men coming and willing to be donors, only 10-50% are able to meet requirements. At the same time, an option of cryo-conservation of one's own sperm for the future is not popular, only very few men ask for that.

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. However, the strain might be even higher in men.

A number of studies (Abbey, Andrews, & Halman, 1991; Akizuki & Kai, 2008; Miall, <u>1986</u>; Mindes, Ingram, Kliewer, & James, 2003; Sandelowski & Jones, <u>1986</u>) have indicated that infertility and fertility treatments are associated, both in women and men with deep and intense psychological problems. 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, <u>2007</u>). However, though many female IVF patients, driven either by conscious decision or by their emotions, search for support not in their inner circle of friends and relatives but elsewhere, for example in the Internet-communities, male IVF patients seem not to discuss this matter neither with friends, nor with female partners, nor in the Internet, in spite of the fact that the longer the treatment takes, the more acute the need for support becomes.

Research (Awadallah, <u>2006</u>; Bäckström, Wahn, & Ekström, 2010; White & Dorman, <u>2001</u>) 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 wellbeing of those involved. This is the case with real life patients' support groups and with those formed on the Internet (White & Dorman, <u>2001</u>).

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).

We will analyze here the attitudes and behavior of men with fertility problems as mediated through their wives perceptions, expressed on the Internet-forum, uniting infertile couples. We have to do so because it is extremely difficult to find or generate males' own accounts of infertility due to over-sensitive nature of the topic.

Aims and subject of the study

The main goal of this article is to investigate the lived experience of fertile or infertile female partners of infertile men in Russia, as revealed in forum discussions within their Internet community.

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.

Lipnack and Stamps (<u>1997</u>) and Mowshowitz (<u>1997</u>) 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 (<u>2008</u>) even suggests that Internet communities can be harmful because they lead to attitude polarization and increased prejudices amongst their members. 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 specific objective consists of understanding the role the specific community of wives of infertile men might play in providing their members with social support, information and understanding of how to react on their male partners behavior and attitudes concerning the latters' infertility.

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.

According to Kozinets, the basis of netnography is the observation of textual discourse. Accordingly, hermeneutic qualitative discourse analysis is the main method for us while examining the data.

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

The interactive forum of the site <u>www.Probirka.ru</u> 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 40165 registered users on 13 October 2011. It exists 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 patients' communication.

The ART patients from all Russian regions come together here. In addition, there are many Russian-speaking women 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. Attitudes of male partners to treatment concern precisely this 'philosophy' issue.

One of the authors' coming to the forum was perhaps prompted, at least in part, by a need for belonging, since she had an experience of IVF treatment herself. Eventually she physically met up with many other women belonging to the community.

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

On the whole, there are about 50 participants of the sub-forum "Male factor". They are from Moscow and other Russian cities.

For this article, only the discussions on this sub-forum were used⁴.

These discussions were chosen because they provide information on the lived experiences of the participants as (fertile or infertile) female partners of infertile men, going through IVF treatment and trying to find people who can socially and psychologically support them.

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, based on the assumptions that both language and culture are constitutive as well as constructive (Lindlof & Taylor, <u>2002</u>). The EOC provides the possibility of using ethnographic

⁴ They can be found at (all assessed 13th October 2011): http://www.probirka.org/forum/viewforum.php?f=7&sid=c2e5b71e698a8196939f56eea27dc1dc

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 topic of discussion is usually pre-established by one of the group members, but is then being 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. 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 (<u>1993</u>)).

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 not mention at all. Accordingly, the Internet is the only space where one can find discussions on such topics (Solomon, <u>1996</u>).

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 <u>www.Probirka.ru</u> 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, 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.

Summary of findings, discussion and conclusion

A comprehensive understanding of the findings might be summarized as follows.

Men reactions at the fact of their infertility seem to be passive, their "first shock" acquires a form of denial and rejection, accordingly, nothing is being done:

"We have male factor. And what I was the most surprised with, when my husband learned about this, he somehow became... calm. He supports my desire to have children, but when he heard that naturally we cannot conceive, he just stopped thinking about this, like, it is impossible, then, ok." ZML.

Often, energy is redirected in the other areas, while desire to have children is problematized or reconsidered (according to their female partners' view).

"He went through one course of treatment, no result, and he said that he has no money to continue treatment. But in reality, he has money to buy very expensive gadgets... He still asserts that he wants to have children, but does nothing to achieve this, as far as I can see", ZML.

Strategy of "not speaking about" is universally chosen.

"Well, it is put into them by nature, that they are MALES and no other way, but sometimes they are weak in something due to some factors... but they pretend to be strong, they do not tell anybody, but wife, who once has said "together in joy and sorrow"... ", MMYU.

"Our men simply are deeply hurt that they "worse" than other men, is any of your men able to discuss his male factor infertility with relatives or acquaintances??? I doubt it! Man is supposed to be strong, while here, there is his weakness!!! Our men are afraid of their imperfection and of unclear situation which they cannot understand. They feel ashamed and morally difficult to call doctors and admit their own inadequacy..." ZMY

"The trouble is that my husband became alien, he constantly avoids answering me, he is always busy for me, cannot speak to me, he is always sitting beside computer in headphones". OF

As a result of all of this, treatment, if there is any, is totally in the female hands.

"I have seen once how someone husband just ran away from ova puncture procedure, so much he was afraid to produce a sperm sample... so that his wife, just after a puncture, and a doctor both were running after him in the hospital corridors and tried to persuade him not to be so nervous and to return..." MMT.

Moreover, even the scanning and testing of the sperm, though it is supposed to take place in the beginning of a couple treatment, often happens only after years of female partner being tested through: "I think it is how we can support them – by going through analyses and IVF cycles even before he ever produces a sperm sample for the test "LNK.

Women generally prefer to take these matters, as all matters of family health, in their own hands, and do not expect their 'male factor' husbands to be active:

"Is it really bad, in your view, that some matters in the family might be delegated to a wife, while others – to a husband? Telling: I trust you, you can do this better... he has his own sphere of responsibility, and I have mine. So all the procreative issues are mine", YOZH.

Some women however prefer all these practices to change, and try to understand what can be the ways of changing men behaviors and beliefs in this area:

"All woman sacrifices should be motivated by man behavior, activity, readiness to do something to have a child. If he does manifest none of this, a woman should better think whether her sacrifices are justified and have any sense", YOZH.

All this seems to be just another aspect of Russian males' behavior in health matters being passive. Accordingly, if cultural practices and ideas in this area would not change, prognosis for male infertility resolution becoming more frequent in this country, are probably pessimistic.

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