

# Risk Communication in Assisted Reproduction in Latvia: From Private Experience to Ethical Issues

Signe Mezinska, Ilze Mileiko

The Centre for Bioethics and Biosafety, University of Latvia

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The aim of this paper is to analyze the process of risk communication in the context of assisted reproduction in Latvia. The paper is based on a qualitative methodology and two types of data: media analysis and 30 semi-structured interviews (11 patients, 4 egg donors, 15 experts). The study explores a broad definition of risk communication and explores three types of risks: health, psychosocial, and moral. We ask (1), who is involved in risk communication, (2), how risks are discussed using different channels of communication, and (3), what ethical problems arise during this process. In the process of analysis, we identified four types of information channels and two strategies of risk communication used by patients, as well as several ethical problems. In our view, the analysis of risk communication practices is significant to improve patient/physician relationship, as well as better meet patients' needs for comprehensive risk information.

*Keywords:* assisted reproduction, risk communication, patient/physician relationship, reproductive ethics

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## 1. Introduction

Since the introduction of detailed informed consent requirements in the second half of 20th century, patients have more choice and better access to information about health risks and benefits. Their personal values are also treated with more respect. Risk communication, an exchange of information and opinions concerning risks, has become an important part of the patient/physician relationship. It is an important prerequisite for health-related choices and has long term implications for patients' well-being. Success and safety in the use of medical technologies largely depends on ade-

*Corresponding author's address:* Signe Mezinska, Kronvalda Boulevard 4, Riga, LV-1010, Latvia. Email: [signe.mezinska@lu.lv](mailto:signe.mezinska@lu.lv).

quate discussions, between physicians and their patients, about uncertainty, expectation and risks (Webster 2002, Alaszewski and Brown 2007). In the case of women who are undergoing infertility treatment, it is important to be involved in a well planned risk communication dialogue, because research shows that it helps to reduce feelings of fault and self-inflicted guilt in cases of failed fertility treatments (Silva and Machado 2010).

Unfortunately, recent studies provide empirical evidence that in the process of assisted reproductive technology (ART) with informed consent, users do not receive adequate information regarding risks (Laufer-Ukeles 2011, Rauprich et al. 2011). Some authors argue that because existing practices of risk communication represent negotiations of knowledge between experts and lay people, they reproduce existing social power imbalances (Silva and Machado 2011). Research studies investigating the role of alternative sources of information (e.g. peers or the Internet) in the process of risk communication (Kaliarnta et al. 2011, Lampi 2011) have prompted some researchers to believe that a broader, more contextual, and relational perspective on risk communication should be applied (Laufer-Ukeles 2011). To improve practices of risk communication in health care, various communication channels need to be analyzed to account for the experiences of ART patients, and the procedure's ethical aspects.

The aim of this paper is to analyze the process of risk communication in the context of ART use in Latvia. We will identify those involved in risk communication, how risks are discussed over certain channels of communication, and what ethical problems might arise during the process of risk communication.

## **2. Theoretical background**

### **2.1 Theory of risk communication**

The theory of risk communication became a subject of specialized study in the 1980s. The guiding approach at that time was the Information Theoretic Model, depicting risk communication as a linear process where a signal travels from a single source (usually authoritative, such as a medical professional) to a lay audience (Krimsky 2007). Krimsky uses the term "narrow definition of risk communication" for this approach, wherein the content of the "risk message" in medicine defines only health risks, only experts serve as a source of information, and the flow of the message is directed from experts to non-experts through institutionalized channels (Krimsky 2007, 158). In its narrowest sense, then, risk communication in medicine is often analyzed within the framework of informed consent. The aim of informed consent is to ensure that patients grant permission to procedures only when they know the objectives, methods, risks, benefits, and consequence of medical treat-

ment. This framework tends to instrumentalize risk, using object-centred and problem-centred approaches that concentrate on physical aspects of risk as opposed to subjective risk perceptions.

One of the important catalysts for change in the definition of risk communication was the emergence of the Internet, which significantly altered practices of information exchange (Krimsky 2007). Also the new non-paternalistic models of patient/physician relationship significantly influenced the flow of information. In contemporary multi-stakeholder frameworks including patients, their relatives, physicians and broader society, health-related risk communication is described as a multi-directional and non-linear process which goes beyond the informed consent procedure. The ‘broad definition of risk communication’ as offered by Krimsky (2007) includes more channels of communication, covers a wider range of risks and involves more sources of information. Here, risk is viewed as socially constructed, and experts are not perceived as the only reliable source of knowledge (Krimsky 2007, 158).

In this broader sense, the content of risk communication is any form of individual or social risk, conveyed by any source. In other words, the message may flow from any source to any recipient through any channel. In our analysis we will use the broad definition of risk communication to explore the growing complexity of the field, and to include more types of risk and channels of risk communication.

## **2.2 Risks in assisted reproduction**

ART is perceived as “hope technology” (Franklin 1997) with the potential for new promising and effective solutions to infertility problems. Unfortunately ART has also created new threats and risks for patients’ health, as well as social and psychological well being, which are communicated to the patient in terms of probabilities and uncertainties (Alaszewski and Brown 2007).

There are several groups of risks with a causal relationship to ART. The first group includes health risks, which are assessed by empirical data, or the measurable components of risk. The communication of statistical data to an individual patient is accompanied by statements of probability and uncertainty regarding the patient’s possible outcomes. For female patients and egg donors, health risks include ovarian hyperstimulation syndrome, and infection, alongside possible long-term effects and multiple gestation pregnancy (Land and Evers 2003).

There are also health risks related to the welfare of the future child. Some studies show that there is a slightly increased risk of birth defects among children born by IVE, compared with the general population. Conflicting studies show, however, that this statistic disappears when risk factors such

as parental age are controlled (Reddy et al. 2007). The risk of accidental consanguinity between anonymous donors and patients is also mentioned as a considerable health risk for future generations (Sawyer 2010).

The second group of risks for prospective parents are psychosocial, e.g. the high possibility of failure, depression in the case of unsuccessful treatment, financial loss, and the psychological burden accompanied by multiple births. Research studies show that mothers of multiples have a significantly higher risk of becoming depressed (Sheard et al. 2007). There is also the psychological risk of developing an overwhelming desire for children, which may threaten the patients' decision-making capacity (Rauprich et al. 2011).

The third group of risks are moral in nature. These include dilemmas caused by moral uncertainty, and are characterized by the risk of making an ethical mistake (Moller 2011). Moral uncertainty in the context of ART use includes personal doubts about ethical issues, like questions regarding the use of a certain technology, the status of embryo, and the difference between "natural" and "artificial" reproduction. This group of risks is especially emphasized by religious organizations. In contrast to health risks, psychosocial and moral risks cannot be assessed and managed on the basis of statistical analyses.

### **2.3 The ethics of risk communication**

There are many ethical issues which should be explored in considering how to communicate with patients about the risks of assisted reproduction. These issues may be related to different models of the patient/physician relationship, the role of trust in such a relationship, and the responsibilities of the parties involved. Clinicians and patients may be involved in at least four models of the patient/physician relationship, which in turn affects the decisional priority (i.e. the ability to define the clinical question or dilemma) and the final decisional authority (i.e. the aptitude to make a decision) (Eriksson et al. 2007, 20–21). The four models, as defined by Eriksson et al., are as follows:

1. The paternalistic model, wherein the physician makes decisions in the best interest of the patient and has both the decisional priority and the final decisional authority.
2. The informed choice model leaves the decisional priority and authority to the patient and requires that the patient has a substantial understanding of the relevant information.
3. Shared decision-making seeks a middle ground between paternalistic and informed choice models, involving patients in decision-making "to the extent that they desire" (Edwards and Elwyn 2006).

The decisional priority is held by the physician, but the final decisional authority is offered to the patient.

4. A narrative-based consultation style puts risk communication in the context of the patient's story and the doctor holds "neither the decisional priority nor decisional authority" (Eriksson et al. 2007, 21).

The role of trust in the patient/physician relationship and risk communication is broadly discussed in the bioethics literature (O'Neill 2002). Though the patient's trust in the physician is often emphasized, recent studies show that the physician's trust in the patient is equally significant for successful communication and treatment results (Thom et al. 2011).

The responsibility of involved parties is another very important ethical aspect of risk communication. As discussed in our article "Sharing Responsibility in Gamete Donation: Balancing Relations and New Knowledge in Latvia" (Mezinska et al. 2012), the notion of individual responsibility and autonomy in the context of ART should be further reconfigured so as to be more sensitive to interdependence and relations of all involved stakeholders (ART users, gamete donors, future child, relatives, physician and society).

### 3. Methods

The empirical part of this paper is based on a secondary analysis of data gathered by the European Social Fund's co-financed project, "Capacity Building for Interdisciplinary Biosafety Research". The sub-study on ART is a part of this larger project and aims to develop recommendations for improving biosafety in the field of assisted reproduction in Latvia.

The paper is based on data from 30 semi-structured interviews and a media analysis, which was conducted from September 2010 through June 2011. It covers 57 articles with commentaries in Latvian electronic popular media and online forums discussing ART, published from 2003 to 2011, and totalling 376 pages. The units for analysis were identified using Google's search engine and the following key words: 'infertility', 'assisted reproduction', 'surrogacy' and 'reproductive technologies'. Our content analysis of these media provided background information on the contexts and experiences of ART users and gamete donors, and served as a basis for the development of separate interview guides for patients, donors, medical experts, and policy experts.

The interviews, which were conducted between June 2011 and February 2012, included 11 interviews with ART users, 4 interviews with egg donors, and 15 expert interviews. The interviews were semi-structured and problem-centred, with an average length of 60-90 minutes. Oral informed consent

was obtained from all participants. To arrange interviews with ART users and donors, we approached ART internet forum users, as well as used “snowball” sampling by asking interviewees if they knew others who might be interested in getting involved. From 55 lay persons approached, 15 persons agreed to be interviewed. All patients and donors interviewed were females, aged 26 to 42. Interview questions for patients and donors covered the experience of infertility and the process of treatment or donation, responsibilities of involved parties, views on kinship, as well as their opinions on existing policy and the governance of ART.

Expert interviews included 7 physicians (3 heads of clinics, one andrologist, two embryologists and one psychologist employed by a fertility clinic) and 8 representatives of governmental institutions and NGOs. To recruit experts for interviews, an e-mail with a request for an interview was sent to all four fertility clinics in Latvia, as well as to governmental institutions and NGOs involved or interested in the governance of ART. Our aim was to have all four fertility clinics, as well as all relevant institutions and organizations, represented in the study. Every clinic and institution we contacted was responsive, and suggested experts that could be interviewed. The interview questions for experts prompted discussion of risks in the treatment process, the responsibilities of involved parties, as well as an evaluation of existing policy and governance of ART. All experts were interviewed at their places of work.

The interviews were audio recorded and transcribed verbatim. The coding was conducted by two researchers using Atlas.ti, a computer program for qualitative analysis. Standard practices of qualitative content analysis were used to identify and analyse meaningful segments of the text (Miles and Huberman 1994). In the first level of analysis, we searched for analytically meaningful phrases and sentences in text and assigned codes to them. The two researchers worked together to establish codes using an inductive approach to the interviews. After the first interview was coded, the scheme was applied to the subsequent interviews, though codes were often refined as the analysis progressed. In the case of disagreement about the definition of a code, consensus was reached through discussion. In the second level of analysis, we grouped codes into categories (code families) and gave them labels, so as to be consistent with the themes in each category. In the final phase, we used explanatory methods (Miles and Huberman 1994) and to explain the patterns related to risk communication and explore key themes.

One limitation of this study is the gender of the ART users and donors, who were female. We experienced difficulty in the recruitment of male informants because online ART discussion forums in Latvia are occupied almost exclusively by females. Another limitation relates to the study's design,

which is based on qualitative (i.e. subjective) methods and the small number of informants. Therefore, our findings may not be applicable to the larger population.

## **4. Findings**

### **4.1 Channels of risk communication**

From the interviews, we identified four channels of risk communication for patients: medical professionals, peers, media, and priests. Further, the interviews showed that the nature of the communication channel determines the type of risks communicated through this channel. Though physicians are often the information channel used in discussions about health risks, other risks might be ignored or rarely discussed in this communication. For communication about psychosocial or moral risks, many patients turned to online forums. Priests are another important risk communication channel for religious persons, especially to discuss moral risks.

#### **4.1.1 Medical professionals**

In the patient interviews, physicians were perceived as a key source of information, and viewed as the most important party for communicating health risks in assisted reproduction procedures. Physicians also emphasized their role in explaining risks to patients and donors to create an understanding of the process and possible health complications.

The expectations of patients regarding the content of risk communication varied significantly. Some patients wanted to know all the possible threats and asked many detailed questions. However, several of the interviewees admitted that before the first IVF procedure, they were not willing to go into detail about the risks. They feared that this information could affect their psychological ability to “tune for success”:

... when [the woman] goes to the [IVF] process for the first time, she is not interested [in risks]. When this attempt fails, you read all the internet articles or something else, and you start to be interested what is what, why it is so, and so on. (ART user 10)

Our analysis of the interviews showed that the style of risk communication differs from clinic to clinic. Depending on the personal attitude of the physician and the policy of the clinic, risk communication can be viewed as a formal requirement or a substantial part of the patient/physician relationship. Infertility clinics that work within an international network tended to introduce strong risk communication and informed consent policies.

Well, yes, then there is a list [of risks], and then they explain. In the

clinic X they came again and explained additionally point-by-point things I didn't understand. The clinic Y was not so... (ART user 6)

The patients who were in favour of the informed choice model of risk communication emphasized that during the risk communication process, it is essential that the doctor gives information while allowing their patient to make decisions independently. In this model, the doctor is viewed as a counsellor of sorts, whose duty is to provide advice about the best possible solution and yet remain neutral.

[The best doctor is that] who hears out, maybe does not immediately impose a certain opportunity, and offers several options. Well, [he] tells in detail what happens in one or another case, recommends the best way. (ART user 5)

The quality of the risk communication process is influenced by the fact that doctors often do not believe that lay people (both patients and donors) are able to understand the nature of the risks and make a rational decision. This perspective was expressed by several physicians.

I think that they [egg donors] cannot evaluate the risk, because [lay] people in general cannot evaluate what is happening with their health. (Head of the clinic 3)

In lay interviews, the physician was perceived as the safest option for discussions about health risks, because of his/her expertise and medical knowledge. However, some patients admitted that the patient/physician relationship might be affected by a power imbalance and a paternalistic communication style that does not match their expectations, because it leaves many questions unanswered. Though some patients remain passive in the decision-making process, others try to find alternative channels for risk communication to overcome the limitations of the patient/physician relationship.

#### 4.1.2 Peers

Internet forums were often mentioned as an important channel for peer-to-peer communication of different kinds of risks. This information exchange channel was viewed as a basis for non-asymmetric, free discussion about health risks as well as risks not directly relevant to medicine, e.g. concerns about the choice of doctor, financial burdens, and moral risks. ART users highlighted Internet forums as a space to share experiences, ask for advice at any time, provide easily accessible information, and encourage questions and discussion.

Although that Internet forum is funny, it helps many 'girls', too, and it is very easy to obtain information there. ... In clinics you have to pay big money, quite big for it. (ART user 10)



Informants emphasized that a very important advantage of Internet forums was the empathy and mutual respect (i.e. psychological support) expressed by other women who experienced infertility treatment.

The “girls” know what [to say], because they have experienced it [infertility treatment]. They know what is the right thing to say in specific moment; how not to hurt the other person, because it is such an emotional process. (ART user 5)

The use of simple language was highlighted as an additional advantage of communicating risk through online forums. At the same time, in several interviews with doctors and patients, Internet forums were described as unreliable sources of information. Some physicians said that medical risks should be discussed only with medical professionals, believing that the information in forums can be biased or open to misinterpretation, and therefore requires careful evaluation. The same was pointed out by some lay users:

... if you read there sometimes, well, you understand that things written by some person, well, they are not connected to the reality (ART user 3)

There are two types of Internet forums for discussing ART issues in Latvia : those which are open, and those which are closed to the general public. Open forums allow the broader public to join the information exchange and add a multidimensional perspective to the process of risk communication. Prejudice regarding ART in Latvia persists, which can lead to negative attitudes and the stigmatization of ART users in discussion forums. As a result, online forums can be spaces which host negative or offensive commentary regarding ART.

Thus, the special advantage of closed Internet forums is the opportunity to develop a more intimate and safe atmosphere. Closed forums are often the place in which personal friendships are established and face-to-face meetings are arranged. Since there are no organizations that represent infertility patients in Latvia, certain closed discussion forums serve as a platform for policy initiatives. For example, members of one closed forum were asked for their opinion in a discussion about a national infertility treatment policy development process.

#### **4.1.3 Priests**

In some interviews, priests were mentioned as an important communication channel for discussions regarding moral risks. Some patients said that not all kinds of risks can be evaluated on the basis of medical knowledge or peer-to-peer communication. In their view, ART use involves certain moral

risks and may conflict with their religious beliefs. Therefore they must discuss their decision to use ART with a priest, to evaluate moral risks from a religious point of view.

Of course, the religious dimension is important enough for me, too. I have spoken with priests and [persons] like that, respectively, whether it is interference with the will of God or not. (ART user 9)

The interviewed patients admitted that, oftentimes, communication about moral risks with a priest did not solve dilemmas. Priests tended to interpret ART as an evil, according to the teaching of the Church. Though this attitude embittered patients, they were not willing to give up their pursuit of ART in light of it:

...speaking with the priest, of course, he [told me] that it is not allowed to do it [IVF]. And for a long time I really thought that I need to rely [on God]. ... But anyway I did understand that if the medicine can help then it should be used. (ART user 5)

There were several ways in which religious persons dealt with the conflict between the teachings of the Church and their personal wish to use ART. Some of them redefined the meaning of ART by defining it as God's instrument or comparing it to a blood transfusion, while others tried to find a priest with more liberal views.

#### **4.1.4 Media**

Media analysis showed that ART risk communication is not homogeneous, and there are differences between its portrayal in print and electronic media. Print media is a less important channel for risk communication regarding ART, and they are used mostly as a platform for advertising for fertility clinics and possible treatments. Risk communication in electronic media is dependent on the interests of the provider of information. Although the web pages of infertility clinics could serve as important channels for risk communication, they are rarely used as such. Instead, clinic's web pages are designed to create an impression of reliability. This impression is constructed through the use of certain terms (e.g. 'trust', 'safety', 'quality standards', 'experience', 'qualifications') and images that generate similar associations (e.g. self-confident doctors, medical equipment and babies as a successful result of ART use).

One possible reason why the clinics and their representatives do not engage in broader risk communication is commercialization. The need to maintain profit affects the style of risk communication because it is related to the attraction of donors and patients to the clinic. As a result, psychosocial and moral risks are not emphasized on clinics' websites, and are usually discussed after patients visit the clinic.

Religious organizations and NGOs actively contribute to risk communication related to ART use in electronic media. They popularize their interpretation of risks by commenting on articles about infertility and ART, creating their own web pages, and publishing articles. Religious organizations try to influence the process of risk communication by focusing on health risks for the patient and future child. Moral risks, however, continue to be seen as most important issue at stake in ART. For example, some religious organizations argue that ART threatens the integrity of the individual and the family, the uniqueness of the marriage relationship, as well as notions of paternity and maternity.

## **4.2 Strategies and problems**

In the process of analysis we identified two strategies of risk communication used by patients, as well as several ethical problems in the process of building trust among different parties.

### **4.2.1 Strategies for risk communication**

The interview analysis showed different strategies of risk communication related to evaluation and exploration. Firstly, “exploring risks” may be viewed as an important part of the decision-making process, allowing one to exercise agency regarding treatment choice. “Ignoring risks” was also seen as a viable strategy. The first strategy (“exploring”) conceptualizes risk communication as an active investigation and evaluation of risks, associated with the idea of parental responsibility to the future child. Exploration of the risk may be done prior to treatment, but can also begin during the process or after a failed attempt of assisted reproduction. Failure during the first infertility treatment attempt may lead to additional questions about its safety and efficacy:

In my case it was so that most of the theoretical basis I acquired already after my [IVF] procedure, because before that I did not have time to go into. (ART user 10)

Collecting information about risks is a way for the patient to understand the treatment process and prepare for possible complications:

And then he [the doctor] explains; he answers my questions; he asks whether I do have questions. Well this psychological aspect for me is very important. (ART user 6)

Although many patients demonstrated their agency in the risk communication process, some physicians believed patients to be lazy, claiming that they rarely explore risks themselves. Instead, they rely on information provided by doctors:

I wouldn't say that there is lack of information, but they [patients] are lazy to look for it. (Embryologist 2)

The second strategy of risk communication ("ignoring") was to avoid it, and was characterized by the view that knowledge about risks could lead to negative thoughts and psychological stress, which may threaten a positive outcome:

Of course, it is necessary to tell and explain it [information], but ... the negative information, it should not be. It immediately causes the stress, the anxiety, which definitely do not benefit anyone. (ART user 4)

The commercial nature of ART clinics is another factor that influences risk communication and can sometimes result in patients opting to ignore risks. On occasion, patients/consumers perceived ART as a service rather than medical treatment, and believed that the financial investment guaranteed them a positive result. In other words, some patients admitted to being unwilling to discuss risks because it might threaten the transaction they were making with the clinic. Other patients reported that the payment enabled them to modify their communication style with the physician. It made them feel that they were entitled to certain information and to ask questions. The significant cost of infertility treatment was reported as a factor that might influence patients to ignore a variety of social or medical risks should a possibility to reduce the cost of the procedure arise. Interviews showed that in some cases, sharing eggs during the ART procedure is one way to reduce costs, in spite of additional risks posed by this procedure e.g. consanguinity, psychological risks, or moral dilemmas.

Patients reported that they classified risks according to their subjective significance. Only the risks that might influence the patient personally were perceived as important:

I do not think that I am careless, but from what was told to me I ... immediately excluded ... things which in my view will not apply to me. (ART user 3)

This may lead to the fragmentation of perception, exploration, and memory of risks. For example, donors who hide their health information were perceived as a potential risk, since this can affect the outcome of assisted reproduction. At the same time, patients were not worried about the risks incurred by egg donors, and denied their moral responsibility regarding them. This relationship was portrayed as unjust in some donor interviews:

For what reason this couple, living in their love now will begin to exploit ... on the expense of others. (Donor 4)

Certain risky situations can be viewed as an opportunity from the patient's point of view (e.g. a multiple gestation pregnancy). Physicians emphasized the risks of a multiple pregnancy, such as premature birth and low birth weight, but many patients nevertheless saw it as an opportunity to reduce treatment expenses and have more than one child:

Well, it has been suggested that there it is the risk and it is known, but bearing in mind that we all want to become [parents] for many years, then, well, we're ready for than there is the multiple gestation risk. (ART user 7)

#### 4.2.2 Trust

Trust was perceived as an essential element of risk communication by all stakeholders: patients, donors and doctors. Patients reported that the most important factors for building trust in the physician are education, knowledge, professional experience and reputation, as well as how the doctor communicates and cares for the patient. Deficiencies in communication style were ignored if the doctor's qualifications were assessed as high. The right choice of physician and clinic was emphasized as a very important precondition for the success of ART treatment. The interviews revealed two ways that ART users checked reputation and built trust. First, some patients discussed treatment options with a number of physicians to compare qualifications and expenses. Second, patients discussed their options with peers privately in person, or online. According to the patients, these discussions helped them to reduce risk and choose the best treatment option.

Trust was also linked to the gender of the physician and patient. Women admitted that it is easier to build a trusting relationship with a female physician, while men said it was easier to talk about their problems with a male doctor.

It was confusing for me that all of the doctors offered there are males. Well, it was a terrible psychological barrier for me. (ART user 8)

In one case, the interview analysis showed a significant trust gap between partners. For example, one of the interviewed patients admitted that she had an agreement with the clinic. If her husband would have problems with sperm quality on the day when insemination was planned, and there would be a need to use donor sperm, the doctor would conceal this information from her husband. Her justification for this decision was a desire to protect her husband's dignity and masculinity, and avoid the emotions that could negatively influence his self-esteem and relationship with the future child.

He said, ok, I accept your wish, and it was written in my medical records. In case if on that day when my husband will provide the material [sperm] for insemination, it does not succeed and there is no

result, then with my permission a donor sperm must be used. (ART user 12)

Online forums showed some anecdotal evidence of similar cases, when patients asked physicians to hide information about the use of donor gametes from their partner. This shows that sometimes the trust relationship between doctor and patient involves the exclusion of other persons, e.g. the partner, from such a relationship.

The party least trusted by doctors and patients were egg donors. In some patient interviews, donors were characterized as unreliable persons who hide health information or donate gametes more than three times the number allowed by law. One of the main reasons donors were seen as less reliable by both ART users and doctors was their interest in receiving financial compensation.

## 5. Discussion

Information about possible risks allows patients to participate in decision-making, evaluate the situation and create a more balanced power relationship with the physician. Another vital function of risk communication is the minimization of self-blame, a characteristic common among women after unsuccessful ART treatment (Silva and Machado 2010).

Our analysis of risk communication showed that physicians are viewed as an important source of information about health risks, but are not so involved in discussing the equally important moral and psychosocial risks. For that reason, patients look to alternate channels of risk communication, such as peers, priests, and the media. Risk communication may be hindered by doctors' attitudes when they do not trust patients to be able to adequately evaluate their situation. As a result, these doctors use a paternalistic communication style which leads patients to seek other channels of risk communication. Other authors emphasize that a doctor's lack of trust in their patient has both moral and practical implications: "Patients already lack power in the medical context; being distrusted shifts that balance of power further towards the doctor" (Rogers 2002, 78).

Electronic media have huge potential as channels of risk communication. One recent study shows that the practice of age-related female infertility risk communication in the media reaches "women of all ages, while only about one woman in four has received information from the health care system" (Lampi 2011, 365). Some authors argue that the Internet has led to a new stage of risk communication where "ordinary citizens can acquire, process, and evaluate scientifically grounded information leading them to a less-divisive and more rational consensus position on the risk" (Krimsky 2007, 163). As our informants and other research studies (Kaliarnta et al.

2011) point out, online communities provide important emotional support for ART users. However, ART users who participate in Internet discussions are at risk of stigmatization by commentators. Therefore ART users often opt for closed Internet forums which provide an intimate and safe atmosphere. At the same time, there may be biased information and a lack of balanced and neutral discussion in media spaces about all kinds of risks in assisted reproduction. Physicians are not highly involved in public discussions about ART risks, while religious representatives are very active. A possible solution to this problem could be the involvement of representatives of IVF clinics in already existing discussion forums devoted to the ART treatment experience.

Our study showed that decisions made by patients and donors in the context of ART use are not simply the result of balancing benefits against risks. Risk exploration includes an evaluation and sorting of risks according to their subjective significance. There are many factors influencing an individual's perception of risks, strategy of risk communication and decision-making process. The first factor influencing risk perception is controllability. Research shows that when people feel that they have some control over the risks they face, they perceive that risk to be smaller (Slovic 1992). In situations where people do not see options for choice and control, they are less willing to get detailed information about risks and to be involved in risk communication. Several of our informants saw their infertility as a situation in which they had no choice, leading to their deliberate ignorance of the risks involved in ART.

The next factor in an individual's perception of a risk is the risk to benefit ratio. Some authors (Alhakami and Slovic 1994) believe that the perceived risk to benefit ratio is the crucial factor that determines how much a given threat is feared and/or discussed. If there is a strong perceived benefit in a specific choice, the risk associated with it will seem smaller and less important than when no such benefit is perceived. In the case of assisted reproduction, the greatest perceived benefit is to become parents, and from the patient's point of view, this hope may outweigh many risks and make risk communication meaningless. There are quantitative studies confirming that ART users are so overwhelmed by their desire for a child that they may lose control over the situation, and become limited in their capacity to evaluate risk or end unsuccessful treatment (Rauprich et al. 2011). In such cases, Rauprich et al. recommend access to psychosocial counselling, as well as clear guidance about how to discontinue unsuccessful treatment (Rauprich et al. 2011, 2390).

Another important factor influencing risk perception and communication is trust, which is an essential feature of the patient/physician relation-

ship and corresponds to a patient's self-reported compliance to the treatment procedure (Keating et al. 2004). In the interviews, most of the patients expressed the belief that they do trust the physicians who control the process and risks. This is one possible explanation for why there is a tendency to ignore the risks posed by ART. The more confidence patients have in the professionals responsible for the process, the less fear they feel, which may lead to less detailed risk communication. In some cases, it can lead to errors in judgment, e.g. the case in which our informant asked her physician to conceal information about usage of donor gametes from her husband.

## 6. Conclusions and recommendations

1. Although physicians are reported to be the most important information channel concerning health risks for ART users in Latvia, other sources of information (peers, media, and priests) also play an important role in the process of risk communication. The multi-dimensional practice of risk communication, involving different channels of communication and various types of risk, helps ART users to make more holistic and informed decisions.
2. The risk communication strategies employed by ART patients may change during the treatment process. For instance, failure during the first infertility treatment attempt may lead to additional questions about safety and risks. Although "ignoring risks" may be accepted by patients as a personal choice in risk communication, physicians should be sensitive to possible changes in strategy and respond adequately to the information needs of the patient.
3. An important advantage of online forums is the empathy expressed by peers, the mutual respect for emotional needs and psychological support. A shortcoming of discussion forums is a lack of evidence-based information about the health risks posed by ART. One way to improve such forums is to involve representatives of IVF clinics in existing online discussions established by patients.

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