Bound together by Fate and Faith.
A Qualitative Analysis of Online Discussions on Assisted Reproduction in Hungary

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Abstract: As having children is considered an inherent and accepted stage in family development, the inability to procreate can be considered as a crisis on both a family and an individual level. Receiving infertility treatment is also a life event that may result in significant emotional distress, thus it is equally imperative to concentrate not only on how patients experience their own involuntary childlessness, but how they perceive their successful or unsuccessful treatments.

This paper investigates the everyday life experiences of infertile women who have decided to seek medical treatments which employ assisted reproductive technologies, based on a systematic and in-depth qualitative analysis of topic related on-line discussion group messages. Central focus is on how the participants make sense of their conditions and treatments, what questions they find worthy of discussing and how they communicate among their own internet community. The research investigated the constructions, tones, themes, portrayed topics and problems of the individual contributors, whilst not neglecting the dynamics of the online group.

This unique research design permitted studying the discourse of the participants in a natural, non-controlled environment, where the presence of the researcher had no influence on the results. Main findings suggest the analyzed texts hold a combination of a 'rhetoric of sorrow' portraying disappointment, and a 'rhetoric of hope', latter vocalizing their belief in the technological advancement and their unquestionable and altruistic support of one another.

1   Introduction

The topic of reproductive technologies has been a popular question in the world of natural science for decades. The social and moral implications of these technologies have also been subject to research in the sociological community, but this statement is true to mainly the western European and Anglo-Saxon scientific community. According

to Fasouliotis and Schenker: "the reproductive system has special societal sensitivities' and "the social issues related to the application of assisted reproduction should certainly be interpreted according to this assumption' [1]. When researching the perceptions and impacts of technological advancements (especially more complex and controversial ones) three aspects of interrelated criteria should be taken into consideration: religious and philosophical traditions of the given society, the enacted and bench law of the studied society and public opinion that are most likely imprinted by the former two criteria [2].

The research of the social aspects of reproductive technology has so far been largely neglected by the Hungarian social scientific community. Some demographic research has been conducted in the field, and also some qualitative research done on the public interpretation of stem cell research (see former works of Vicsek and Vicsek and Bauer [3],[4] on other fields biotechnological advancements and public perception), but to my knowledge there has not been any qualitative sociological research done with the focus on those using the reproductive technologies. My exploratory research (that is part of my PhD project and also a grander qualitative research funded by *OTKA grant nr. K 108981*)[1] aims to investigate how the patients undergoing or planning to seek such treatments make sense of their conditions and treatments. What questions they find worthy of discussing and how they communicate among their own internet community. I investigated the tones, themes, topics and dynamics of the online discussant group, focusing on their lived experiences of the treatment.

2   Literature review

2.1   Social construction vs. the deficit model

During the paper the theoretical background of the constructivist model instead of the deficit model is applied, which has been used earlier to study the social perceptions and understanding of complex technology. While the deficit model aims to contrast lay knowledge to that of scientific professionals, the constructivist model implies that lay people have different but not subordinate knowledge and thus can understand technology in their own terms [5],[6]. In this sense it is possible to 'explore what the public knows about scientific issues in its own terms' [7]. A key point of the analysis will be to examine the language and terms that the participants use during their discourse on reproductive technologies and not to examine whether they use the terms sufficiently or if their lay knowledge lacks accuracy.

2.2 Reproductive technology, Assisted reproduction

Reproductive technology is the term describing all current and anticipated uses of technology in human and animal reproduction, including assisted reproductive technology, contraception and many more. Assisted reproductive technology (ART) is the use of reproductive technology to treat human infertility. Treatments that can be chosen according to the needs of the patient vary from taking certain medications for ovulary stimulation, hormone treatments, fertility medication artificial insemination, in vitro fertilization (IVF), gamete and embryo donation, cryopreservation of sperm, oocytes and embryos, surrogacy and preimplantation genetic diagnosis [8].

The availability of these techniques differs from country to country. The treatment of infertility and reproductive technologies are part of the state funded health-care system in Hungary, regulated by the Hungarian Act CLIV on Public Health Care (1997 Health Act) parts concerning reproduction sections 165-184) and its later modification[9],[10]. Patients can receive state funded treatment or fund the process themselves.

2.3 Psychosocial consequences of successful and unsuccessful ART treatments

As having children is considered an inherent and accepted stage in family development the inability to have children can be considered as a crisis on both a family and both an individual level. Childbearing has been considered the normal course of social development and thus involuntary childlessness has been known to have significant and irreversible social and psychological consequences [11],[12],[13]. Hungarian research suggests that coping with infertility has similar methods to that of dealing with death [14]. According to Kapitány and Spéder's analysis [15] of the Generations and Gender Surveys only a very small portion of men and women (1,4% and 2,4%) would consider childlessness as an idea situation Not having children is considered to be a state that is very negative and thus should be avoided by the public in Hungary [16]. This is also shown in the 2006 wave of the European Social Survey, where the data showed that a large portion of the Hungarian population disapproves if one chooses not to have children.[2]

In their study of the psychosocial effects of IVF and GIFT treatments Weaver et al. [17] conducted a series of interviews as well as survey studies on couples who have successfully conceived a child at the end of the treatment and couples who have not. The authors have concluded that there were only few indicators that showed long-term psychosocial adjustment problems (this is contradictory to earlier findings of Leiblum et al. [18] that reported significant differences among women with failed IVF treatments), but they do identify differences in the well-being of these patients "in addition to grief, an unsuccessful IVF cycle may bring out increased feelings of isolation and social estrangement in infertile couples which persist many months after the completion of the treatment programme and which may not be reflected in global measures of

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2   based on calculations by the author

psychosocial functioning' [19]. Similar results were found by Verhak at al. [20]. I argue that a qualitative analysis of the discussion groups could be a design that gives a more in-depth and thus more accurate assessment of the moods and tones of the patients involved.

2.4 Online discussion groups, a source of information and support

Internet communities provide a way for a group of peers to communicate with each other without ever meeting [21]. Many studies have concluded that the users on the internet talk about subjects similarly to real life, but significantly more freely. Sensitive topics are discussed easier due to the anonymity that the online discussion groups provide. They have suggested that people harness their emotions for instance their anger less on the internet [22]. Among many functions of internet communication, one is to offer help and support to others with similar problems. Examples of these are the online-support groups, of which health related issues are a common topic [22].

Health-related online fora present a special segment within online fora, because of the nature of the discussed topics. Tannis has reported that the main reasons for using health related fora online were the following: information gathering; emotional support; inclusion; supporting others; convenience; passing time [23]. Anonymity is a central appeal of these groups and the reason for this can be to avoid stigmatization from society, and also to find people who also need to cope with similar situations [22].

3 Research questions, data and methodology

In my exploratory research I study the conversations in the online discussion forum (group) regarding assisted reproduction. My aim is to investigate how the discussants construct their own infertility and treatment, and what implications they mention when discussing their experiences with regard to the application of these technologies, supposing that the topics discussed in these groups are the ones that are the most important for the patients receiving or considering these treatments.

The method of the research was qualitative data analysis of the selected posts using Nvivo software. The selected forum was chosen after a frequency query[3]. Another criterion for the selection was that the forum had to be readable for the public without registration. This does not mean that posting is not restricted for registered users, but that one must not need to register in order to read the content. The reason for this criterion is based in the ethical requirements of social research. I followed the posts on this forum between 28th of April (2012) and 13th of May (2012), analyzing 870 posts.

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3   http://www.hoxa.hu/?p1=forum_tema&p2=2530&p4=25#hsz18327043

3.1 Ethical implications of the chosen method

Ethical implications may be even more pronounced in qualitative research than quantitative research because of the nature of the topics [24]. In the case of this forum analysis that addresses reproduction these ethical concerns are even more in focus. One implication is the distinction between the private and public spheres, which on the internet is not as clear as on other venues [25]. Both the topic and the source of the data poses complicated questions: Can it be considered exploitation to use these conversations given in a private communication context even anonymously? Even they are unidentifiable is it moral to quote peoples statements on such a private question? Is it in the violations of ethical Internet use to use online discussion groups as a research source?

3.2 Categorization and Coding

Throughout the coding I resorted to both inductive and deductive reasoning. Some of the categories were derived from the theoretical and empirical literature prior to having deeply familiarized myself with the texts. But a number of the categories were created after carefully and systematically reviewing the data [26]. Namely reading closely and interpreting the texts of the posts. New codes were introduced to the parts of the texts that shared the participants' doubts about the doctors and other medical professionals.

4 Main findings

The analyzed texts hold a combination of the *rhetoric of sorrow and disappointment* and the *rhetoric of hope* and the *belief in the technological advancement and the support of one another*. The main reasons for entering the group were to offer and receive support and to obtain information. The suggestions of Tanis were not completely supported, since there were no signs of the participants using the forum out of convenience, inclusion or to pass time [23]. The participants use the forum as a source for gathering information and support, but at the same time also use it as a tool for offering knowledge and lending support for the rest.

4.1 Participants, Group dynamic and hierarchy

The participants vary among several characteristics, but what bounds them together is the lack of fertility and their common hopes in the technique of ART as a cure for their condition. The participants have their own community where they can discuss openly all their experiences and questions regarding the IVF process. Group cohesion could be observed in the communication of the group, even though there was no evidence of the members of the group ever meeting in person. The communication was in no way asymmetric, there was no hierarchy observed within the group of participants. The group although having a strong bond, a very close virtual relationship is very open and supporting towards new comers. Further evidence of this close and supportive group

was that they did not show any signs of harboring jealousy towards each other ("inside group'), when one member of the group had good news at either stages or form of ART.

On the other hand, symmetry was not registered when it came to members of the "outside group'. This is one of the traits generally true to online communication according to Wallace [22]. In this sample the question of inside or outside is much more complex than that of simply being a member of the forum or not. Their categorization has to do with whether the person could conceive naturally and easily, or has to go through the tough process that has led to the application of one of the ART-s. The "outside' does not only represent those who were not part of the discussion, but more in general those women (couples) who did not have any problems with natural conception. The participants of course did not harbor any ill will towards these women, but there was a visible shift in tone when discussing them.

'Sure I am sad many times, feel alone with my problem, of course when I find out that it will not be so easy for me, then I find out at work that a colleague of mine was pregnant without even trying so I had to watch as her belly grew and how happy she was, eyes shining. Of course I was happy for her but cast a stone, inside I was very sad it was not me.:([4]
'And we will all be such better parents then those who had a child in the first cycle and perhaps cannot even appreciate the most wonderful miracle of nature.'

4.2 Looking at the categories with greater detail

4.2.1 Information gathering and seeking support

As mentioned the two most common reasons for participating in the discussion groups were to access information and receive the support of others in the same shoes. In this context the fora were sources of knowledge transfer or a virtual shoulder to lean on. But these two categories are to be viewed as intertwined as well: the role of sharing medical information and experiences based on the analyzed texts is not solely a method for transferring knowledge but also a means for showing support. Sharing their knowledge as a reply to a previous, perhaps anxious posts is a way of expressing that the other participant is in their thoughts. The participants are very knowledgeable and seem to possess a wide range of information on the processes and were eager to *share knowledge*. These are typical characteristics of health related online fora (and other sources on the internet) according to Robinson [21] as well as Tanis [23]. The participants possess knowledge on a variety of issue related topics, not solely about the treatments they have already had first-hand experience with. Many of them have looked into (the depth of the medical knowledge would suggest that they have even researched) other possible treatments, medications, methods, tips that were not yet offered to them by their physicians. They are more than willing to pass the gathered information along to their peers, sometimes giving them a more detailed bouquet of knowledge than received from their treating physicians. It is worth mentioning that the participants might even trust the information received from fellow forum users more than they do

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[4] The original language of the forum is Hungarian, the quotations were translated by the author.

the information given by the doctors (the possible reasons for this will be discussed in detail in the section of the paper devoted to the concerns on the intent of medical professionals).

'Yes, I already know that from the forum. '
'It is a bit sketchy that I have gathering more info from the forum than the doctors.'
'Until then we are here for each other as information sources. What would happen to me without internet...'

The *rhetoric of support* can be mostly found in the posts that express the participants wishing each other luck in any point of the process. Some posts explicitly state their support, while for some the main function is purely to comfort. Comfort is often conveyed through portrayal of positive examples of women who have faced the same problem but have already successfully overcome their childlessness and conceived with the help of assisted reproduction. Many of these examples are of the users themselves, who even after conception come back to "lend a helping hand' and offer support through their own struggle and example.

Support could be categorized in two distinct ways. One covered the posts that offered comfort and soothing to those needing it, the other was *support offered through information*. This was deemed a separate category since it was much more than just offering compassion, but sharing wisdom and experiences, when the other participant was in need of it. Most of the supportive gestures coded to this category were that of sharing personal experiences, mainly events that have happened to them personally or that they have heard of. This may seem trivial from outside the community, but the deeper analysis has shown that this special type of caring had a very good influence on those that were seeking the help of others (it was mentioned several times by participants how getting these types of information made them less anxious).

'You wouldn't even believe how much strength I drew from your post!! '
'I don't think you should worry about that, I have two IVF babies and I was on the pill (Marvelon) before and there was no problem at all. '

Comfort and cheerful thoughts were offered in a variety of ways. It was expressed through saying that they are thinking of one another, or rooting for them. It also occurred that general good mood that they needed was directed at the group via song. As in live communication in everyday life the tones of these messages were light and friendly.

'I don't know why but I have the feeling that everything will be fine with you! ☺ Hang in there! '
'Hang in there and we will spin the days for you, so they will go faster. :D'

At the moments when something went wrong, the participants turned to each other. Since as mentioned earlier, this was a venue where they could be totally open and honest with one another in a group that fully understood the difficulties they faced. The participants used their experiences and virtual friendships to console.

' Don't lose hope for me!!! I also had pink spots. My little boy is four months!! :) Don't even think that there is something wrong! Just hang in there!! '

'Fanni! I am so sorry. But don't give up yet!! '
'Don't lose faith. Maybe you will be the one to strengthen the between cycles spotting thing. :)'

4.2.2   Concerns

Though there was a general optimism expressed regarding the techniques, the analyzed texts showed signs of concerns as well. The theoretical literature mentioned a wide array of possible concerns: moral, ethical, legal, social, material and medical. These categories were created but the research shows that not all of them appeared on the analyzed forum. Ethical and legal concerns are dominant in the literature, but they appeared only marginally in the analysis.

Material concerns

Contrary to the moral, legal and social implications, the issues of costs and economic hardship were discussed in detail. The topic of financing the treatments was one of the issues discussed in great length. The costs of the treatments involved were discussed in great detail. This is most likely because it takes quite an effort for the patients to produce the resources needed for the treatments. This lack of resources was one of those discussed topics that had focuses outside of the group, they reflected on how these concerns also effected the general public (the other such issues were the problems with doctors and in general the Hungarian healthcare system). The material concerns were often paired with concerns about the intent of doctors and the general state of the Hungarian healthcare system. These topics will be analyzed in detail in the next section of the paper.

'I have already written to him. The only thing holding me back is the money. Unfortunately we do not have enough for a private clinic. Now I am trying natural remedies.'
'Well yes, if someone doesn't have money they can just go in the gutter.'
'Oh my, that is not little money .It is good that there is three month between cycle, we can get ourselves together a bit.'
'Yes until there is proof in your hands it feels like money thrown out the window.'

Medical concerns

The assumption that the users of the forum may have medical concerns or doubts about the treatment that they receive, worrying about the possible health implication or complication were justified. There were some negative side-effects discussed, but it was never considered to omit the treatments due to these.

Doubts in doctors and the health care system

Within the category of doubts about doctors, distinction was made between the intent and the knowledge of the medical professionals. This was one of the categories that were refined after the initial coding. Doubts in the Hungarian health care system itself, was also a category established after assessment of the texts.

The category that viewed discussions on the doubts in knowledge was less significant. Mainly it was stated that there are special fields where the professionals have less or no experience and thus the proportion of misdiagnosis among the infertile women is rather

high. It was highlighted that the gynecologists have limited knowledge of diagnosis and treatment of endocrinological malfunctions, often not curing fertility problems correctly.

The question on the negative intent of medical professionals and this type of misconduct was discussed in greater detail. Intent had more to do with caring and personal affiliation and not factual knowledge. Several post were about the doctors simply not caring about the patients, not treating them as human beings, just as a case that has to be solved. For instance, when an IVF cycle needed extra attention from the medical professional.

A large portion of the discussions were devoted to how the intentions of the physicians are primarily not to help those in need, but merely to make a profit. Disappointment was expressed towards doctors who in their view do not put the interest of patients in first place but only 'go for the money'. Often they feel used just for the profit. In a later part of the paper it will be emphasized that the tone of these posts were dramatically different from the rest of the analyzed texts, here and only here was there anger and frustration, along with very harsh language. There were posts that mentioned the professionals who were deemed to be unqualified, using the name and location of the practice. This served as a warning for those patients who were thinking of looking that physician up.

'I soon won't believe in any doctor any more, it is only routine for them. They don't check out the things, they only do IVFs. Now I'm thinking of laparoscopy because I haven't done it before.'
'He didn't give a damn about me, wanted to be over so he just got rid of me.'
'Because they are apes. I'm sorry.'
'Yes it was Dr. Kovács. I too felt totally betrayed.'
'Unfortunately all I see is business interest since the more you go back, the more medicine you buy and the more treatment you have, it is all just money, money, money for the clinics. ☹'

Naturally not only the negative aspects of treatments were discussed, quite a few doctors, specialists were mentioned with praise and respect, but compared to the negative messages these were significantly less dominant.

The picture painted about the Hungarian health care system was anything but positive. The long waiting periods and the inefficiency of the health services were at the center of critique. The participants also debated whether it was in fact even worth paying social security, since they felt that when they were in need they did not receive sufficient benefits.

'This healthcare is just great!!! I love it!!!'
'Forget why you pay social security! We don't ask useless questions. ☺'
'Unfortunately that is true. It doesn't matter if you have social security if you want something you have to go to a private facility. And this is not just true for gynecologists. Last August my kid got allergy and we got an appointment for the end of October. But the assistant kindly gave us the number of the private practice of the doctor and got an appointment in two weeks…so no comment.'

The notion that the entire Hungarian health care system is inadequate is an opinion that is introduced rather often. It was not an uncommon idea that after severe disappointment they would go abroad to receive treatment in the neighboring Austria.

4.2.3   Tones of the analyzed posts

The identified tones reflect the general moods of the text, the inclination of the participant. A myriad of useful information can be derived from viewing the tones, they express a great deal on how the participant construct and conceptualize their situation. From the general and unique tones of the posts it is possible to see which topics are more important, what are the issues that have the participants more concerned, what topics make the conversations more relaxed or more heated. Also the tones reflect the psychological, emotional state of the participants, which is of particular importance when studying a topic such as assisted reproduction. During categorization six tones were specified to typify the posts (these respective tones were: angry, hopeless, optimistic, pessimistic, wishful and worrisome).

Interestingly the angry tone in writing was confined only to those posts that were about the inefficiency of the Hungarian health care system, or the posts criticizing the intent of the medical experts, mainly the profit oriented doctors. When describing their own conditions of infertility the tone was neutral, at times even pessimistic, but when describing their hopes in the technological advancements the tone was foremost optimistic.

As could be expected, when the treatment was unsuccessful, the participants lost their optimism and the moods and thus the tones changed a great deal. Hopelessness though was expressed to a lesser extent than optimism, used only in the case when something went dramatically wrong. The hopeless tone was the most intensive one identified, compared to the pessimistic tone (described below) showed deeper sorrow, and raised questions with the effectiveness and the usefulness of the whole process.

'I'm totally out of my mind, my life is worthless, they took away my chances for a whole family.'
'I'm more and more disappointed, I can't even believe in the success any more. :('
'I don't know where to go on, everything is so messed up in me. ☹'
'Somehow I don't feel anything, I think I gave up.'

The wishful tone was used when the participants were trying to imagine an ideal world where childlessness and problems with conception would not be an issue. Though this tone was not expressed directly a frequently in the posts the sense of this longing was present throughout the entire analyzed period.

'You are sweet but what would be the best if this were natural for everybody. What beautiful world we would live in! ☺'

The tone of worry was not uncommon during the waiting period of their treatments. Worry was paired with being inpatient and anxious. These observations coincide with the arguments of the literature that states the most emotionally taxing period of the IVF treatment was the waiting to see if the conception was a success [19].

'Yes I feel. Petrified☺ but really :S'
'It is so bad that I can't relax because of this ☹'
'I will go crazy tomorrow afternoon I will have my results.'

4.2.4 Language used on the forum

The participants on the forum seem to have their own language, one that might seem odd to those who are not familiar with the terms. The language of the fora takes the specific medical terms and uses them in a fashion as if they were nicknames. This possibly adds a sense of friendliness to these cold medical terms, but some are simple abbreviations that can be examples of making the conversation easier ('aunt flow', 'babying', 'stimu'). Support was offered also through words that represent closeness, such as 'hugs', 'kisses'.

After running a frequency query on the text in NVivo, the result was not surprising: the words that appeared most frequently in the texts were medical terms or expressions related to pregnancy and words offering support to the other participants of the discussion group.

4.2.5 The use of emotion icons

As in non-virtual communication, words are not the only form for conveying thoughts and emotions. To substitute gestures a special language is invented, namely the language of emotion icons. These symbols help explain the meaning or tones of communications online. Wallace [22] considers these icons "softening devices' that make the formal written communication more like a live discussion; also they serve a purpose of quick impression making. The intimate and comfortable atmosphere of the fora that make the posts feel closer to actual conversations are partly achieved with the use of icons that express emotions. There are several used in the conversations, most of them expressing joy or sorrow. The most commonly used symbols in the sample were: ☺, :D, ;) to express happiness, and ☹, :'(to express loss or sadness, and :S to express frustration or confusion.

Conclusions

The aim of the presented research was to investigate how (a certain group of Hungarian) patients undergoing or planning to seek such treatments make sense of their conditions and treatments. What questions they find worthy of discussing and how they communicate among their own internet community. Infertility or inability to conceive a child naturally is a very delicate topic that can only be successfully investigated with subtle, non-intrusive methods. Forum analysis permitted me to have no influence on the natural flow of the communication. The presence of the researcher in this case did not influence the topics of the debate and had no effect on the tone and dynamic either. I investigated the tones, themes, topics and dynamics of the online discussant group focusing on their construction of the treatment.

The results of the qualitative data analysis using NVivo software and reviewing over 870 unique posts (using both deductive and inductive coding methods in two steps

[26],[27]) showed that contrasting prior expectations the participants did not engage in discussions about the moral and ethical implications of assisted reproductive technologies, but did address their material concerns. Reports of high levels of stress and emotional volatility were found, focusing mainly on feelings of hope or despair and emotions of anxiety and frustration towards the health system and the experience of objectification from members of the medical community. Personal conflicts and affiliations influenced the participants' discourse on medical professionals, and they also set the tone for the discussions. As reported by treated patients the physical afflictions also caused severe emotional distress for the patients contributing to their feelings of powerlessness and isolation. Besides the rhetoric of hope in technological achievement, a rhetoric of disappointment with doctors and the healthcare system was also influential in the analyzed texts.

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