

Doctoral School of Sociology and Communication Science

SUMMARY OF THESIS

Zsófia Bauer

Narrated experiences of medically assisted reproduction in Hungary

Supervisor: Lilla Vicsek Ph.D. associate professor

Budapest, 2021

Department of Sociology and Social Policy

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1. Background

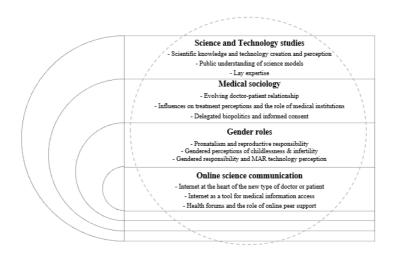
The thesis is focusing on the biographical disruptions and lived experiences of female patients using medically assisted reproductive technologies in Hungary. In general, the aim of the thesis research was to explore patients' constructed narratives about infertility and reproduction technologies and treatment. Further goal was to understand the role of their accumulated knowledge in the form of 'lay expertise' and how it has affected interactions with medical professionals and perceptions of the doctor-patient relationship. Moreover, the inquiry aspired to uncover how the gendered reproductive responsibility of pronatalist Hungary influence participating women's actualities and experiences.

The societal relevance of the project can be grasped in several ways. There is a low rate of children being born in Hungarian society and demographers argue that there is a demographic crisis (Kapitány, 2015; Kapitány and Spéder, 2019). According to the Hungarian College of Obstetricians and Gynaecologists and the Hungarian government, up to one-fifth of the couples in Hungary are infertile. The

number of couples facing involuntary childlessness or having a smaller number of children than originally planned due to infertility is likely to continue increasing in the future in Hungary and around the globe (Kapitány, 2015; MHCH, 2019; Soini et al., 2006). There has been quite a great deal of research conducted to explain declining fertility, yet one of the factors, infertility and trouble with natural conception has been neglected till recently in the Hungarian sociological community (relevant exceptions being the works of Ivett Szalma (Szalma, 2014; 2021), and Lilla Vicsek (Vicsek, 2018; Sándor, Vicsek and Bauer, 2017; Vicsek, Sándor and Bauer, 2021). Furthermore, the inquiry into medically assisted reproduction is of elevated importance, as the number of medically infertile couples is continuously growing (Anderson, 2005; MHCH, 2019), and more and more couples choose to have a child taking advantage of these technological innovations. Thus, since many aspects of infertility and medically assisted reproduction, along with the interlinkages between technology and Hungarian society are still left to unveil and analyse, the findings presented in the doctoral

dissertation can prove relevant to both the Hungarian and international social scientific community.

The thesis attempts to investigate the issue from four diverse and distinct fields of sociological inquiry as depicted in the model below.



The four approaches the thesis gains inspiration from are the following: (1) science and technology studies (STS) to explore the connection between lay public and complex technologies; (2) medical sociology to trace what factors contribute to the new type of doctor-patient relationship apparent today; (3) gender role theory to engage the fact

of gendered reproductive responsibility and genetic burden fuelled by the pronatalist rhetoric and social policy of Hungary; (4) the unique position and effect of online science communication on the aforementioned phenomena and mechanisms.

2. Research questions

Grounded in the above sociological traditions the thesis formulates four general research questions:

RQ1 How are the experiences of patients during medically assisted reproduction narrated in online discussion communities?

This research question explores the main themes, topics and appearing narratives driving the online conversations, with the aim to unveil what focus points and discussion topics are salient for participants of online patient discussion communities. Robinson (1991), Tanis (2008) and Nettleton et al. (2005) all emphasize the important role of these online communities in the lives of patients, especially when the biographical disruption is as severe as in

the case of infertility, and the treatment so emotionally taxing as medically assisted reproduction.

Wallace (2006) has highlighted the importance of online group cohesion and uniquely phrased, but commonly understood language from a cyber-psychological perspective. Through the thematical analysis of these online traces and messages, the emotional drivers were explored, along with the most important semiotic expressions and a specific 'infertility patient dictionary was compiled.

RQ2 How does accumulated knowledge, having contextual lay expertise influence experiences of medically assisted reproduction?

This second research question looks at accumulated knowledge from a science and technology studies perspective, to see how lay expertise is represented and how it can be identified, relying on the theoretical concepts of Wynne (1991; 1992; 2006; 2008) dimensions enumerated by Myskja (2007). The question also deals with open source and experience based, contextual knowledge (Lambert and Rose 1996 or Kerr, Cunningham-Burley and Amos, 1998). The theoretical decision was made to interpret lay

understandings from a constructivist rather than a deficitbased approach, adhering to Brossard and Lewenstein's (2010) framework of public understanding of science (PUS) models. While answering this research question it will also be investigated how the lay knowledge is utilized in conversations and in accounts of the treatment process – does it affect the relationship towards health care system or communication between the doctor-patient dyad (Molnár et al., 2018; Rózsa, 2016).

RQ3 How is the doctor-patient relationship represented and presented in the conversations?

The third research question focuses on the doctor-patient dyad and the dynamics of their relationship. It examines the experiences and stories of the patients and reflects on the functionalities and dysfunctions grounded in concepts of medical sociology (Barker and Galardi, 2011; Cockerham, 2017; Hafferty and Castellani, 2019; Henderson, 2010). The question investigates how the tensions, conflicts, and disruptions are portrayed, and attempts to make a connection between the lived experiences and the doctor-patient relationship models of medical sociology

starting from the traditional, hierarchical, and paternalistic Parsonian framework (1951) to the complex and patient-centered Mead-Bower model (2000).

RQ4 How do gender roles and gendered genetic responsibility influence the Hungarian patients' narrated experiences?

The last research question explores the gendered nature of the infertility and medically assisted reproduction topic (Parry, 2005; Rivkin-Fish, 2010). It looks at how mechanisms of pronatalism and gendered prenatal roles are present throughout the narrated patient pathway relying on concepts of Reed (2011; 2012) discussing the patterns and unequal burdens of gendered reproductive and genetic responsibility.

3. Methods

A multimethod qualitative approach was employed in the thesis research, relying on three distinct qualitative methods – netnography, in-depth qualitative interviews, and expert interviews – but the dissertation focuses foremost on the introduction of the results from the netnography and

uses the other two qualitative methods as relevant reference points and context for the findings. By also analyzing the interviews the methodological design of the thesis research allows for comparisons to be made to highlight how both passive and active qualitative approaches, and thus the combination of online and offline data can yield insights into the life-worlds of infertility patients.

Netnography is a form of qualitative research, a unique form of digital anthropology, an organized set of research tools – a specific way to conduct online and social media research (Kozinets, 2015; 2020; 2021). During the data collection for the dissertation, a more inclusive approach to data isolation was applied, building on both data generated on social media platforms, but also on other channels of the Hungarian web-sphere. The data for the netnographic explorations were isolated and collected using social media monitoring software. The online tool gathers open web data based on search algorithms, keyword-based syntaxes, language, and geolocation filters. The data collection procedure is preceded by an exploratory online research phase where the author investigated

and compiled the keywords needed for the algorithmic software-based data search and historic database compilation. In this phase, the author scoured online forums and edited content to grasp the words, phrases used in online conversation. Keywords, 17 targeted sources, and 150 channels and platforms were compiled into a 'topic query' using Boolean operators. To create the final syntax technical filters – pinpointing data sources by the Hungarian language, and geolocation-based on Hungarian IP addresses – were also added with the use of Boolean operators. Overall, 10 unique syntaxes were created using the combination of 524 keywords. These operations lead to a 'Full raw database of 91 735 results coming from 8 667 unique online sites. After applying the operational filters 11 833 results remained in the filtered database. The largest drop in the number of results was after filtering them for comments and weeding out the duplications with the use of the analytics software. Algorithm-based filtering was used to rid the raw database of identifiable bots, spam, and pornographic content. The filtered data was read and manually to exclude mentions that were grabbed based on the above criteria but were not meaningful to the scope of the project. From the relevant chunk of data, a randomized sample was filtered. The final online dataset was achieved by additional sample filters and consisted of 3004 relevant, non-duplicate, unique online comments and posts coming from 232 unique sites.

The thesis research also relied on the analysis of 18 qualitative patient interviews and 12 semi-structured expert interviews. The participants of the eighteen patient interviews were all women, who had or were involved in ongoing assisted reproduction cycles. One of the limitations of the research is exactly this, that men proved to be an unreachable population for us. Due to the manner and topic of the research the snowball method was used to find the participants for the research, which proved more difficult than expected leading to one of the main limitations of the thesis research, that only the narratives of women were reached.

Both the online and offline data were the subject with rigorous qualitative thematic analysis guided by the six-step framework and guidelines presented by Braun and Clarke (2006). Whilst, the dissertation focuses on the full

spectrum of the themes identified in the online corpus, the findings from the interviews' analysis appear with specific focus on the research questions.

4. Results

The introduction of the main results of the thesis research follows the logic of the research questions presented earlier. All results added diverse, but important dimensions to the aim of the dissertation namely, to broaden, reassess and significantly deepen our knowledge and understanding about infertility treatments foremost through the indepth and rich analysis of the experiences and constructions of infertile patients within the different branches of the Hungarian health care system.

4.1. Narrated experiences unveiled in online discussion communities

The outcomes of the thematic analysis of the online trace data of the netnography gave an exploratory, yet holistic overview of the structure, themes, emotional drivers, and unique use of language in the online space.

The results suggest as follows:

- Four typical patient pathways were identified and categorized within the stories: (1) linear successful; (2) linear unsuccessful; (3) cyclical successful; (4) cyclical unsuccessful. The online conversational data shows an organic structuring along these paths, highlighting emotional orientations of the patients and the conversation topics they discuss.
- made up solely of female participants, and group cohesion in these clusters were observed. While there was no intended asymmetry within the members of the groups, there was a deep demarcation observed between inner and outer groups. The main prong of this differentiation was the ability to have a child. The narratives of inadequacy and social stigmatization were highly relevant in these conversations, and while envy could be seen, these sentiments were confined to the inner emotional struggles of the patients, while the relationship

- between patients and professionals was marked by more conflict.
- have developed their own terminologies, words, and phrases to talk about medically assisted reproduction. While the hyper-formal, textbook medical terminology is very technical, cold, and unrelatable, these concepts are translated into more emotional, engaging, and empathetic words, making up an entire dictionary of infertility-related, nickname-based terminology. This manner of expression possibly adds a sense of friendliness to these cold medical terms, and some of the abbreviations make both the communication process, and comprehension easier.
- Thirteen main themes were identified in the dataset, which are all introduced in detail in the dissertation and connected with its theoretical foundations. These hubs of conversations are the following: (1) Hopes & Doubts, (2) Meaning of childlessness and infertility, (3) Feelings of motherhood (4) Understandings of technology, (5) Knowledge

transfer, information seeking, (6) Medically assisted reproduction in the Hungarian health care system, (7) Doctor-patient relationship, (8) Physical and emotional wellbeing, (9) Material concerns, financial burdens, (10) Alternative solutions, (11) Personal relationships, (12) Social, moral and ethical dilemmas, (13) Interpretations of time.

4.2. The role of lay expertise

The small scale netnography proved a valuable methodological route to unearth evidence of how some patients become and continue to act as lay experts in their communities throughout their assisted reproduction treatments. Infertility-triggered biographical disruption experienced by the patients is serious, complex, and suggests a long-term relationship with the medical system. Findings of the thesis research show that there is a unique knowledge accumulation accompanying infertility and medically assisted reproduction. The results suggest as follows:

- Five clusters of information gathering motivations have been identified through their online expressions. Users engage in online discussions for the following reasons:

 (1) gathering information to better understand treatment; (2) seeking knowledge to better communicate with doctors, to be able to pose all the questions they have about treatment; (3) accessing ample information to question their doctors' authority and knowledge about treatments; (4) searching for alternative medical solutions such as homeopathy or herbal therapy to replace institutionalized infertility treatment; (5) searching for alternative medical solutions such as homeopathy or herbal therapy to complement institutionalized infertility treatment.
- Knowledge accumulation either supports patients in understanding what is happening in the institutionalized health care system (along with their formalized relationship with medical professionals) or grounds their foundations for questioning its authority or turning away from it completely. The latter of these is less common and mostly connected to multiple failures and unsuccessful stopped cyclical treatment pathways.

- A variety of referenced sources shows us a similar discombobulating picture, as the level of knowledge itself.

 There is a spectrum regarding the validity of the sought information: starting at the most basic, non-verified sources, going all the way to citing results from medical journals and lectures.
- The analysis of the online conversations showed that some participants valued the information they gained from the forum more than that obtained from medical professionals, exactly because they did not rely on textbook knowledge, but their own infertility treatment experiences. Arguments were made that infertility professionals do not have this type of understanding – especially since the Hungarian clinical setting is dominated by male experts, and who lack female bodily experiences.

4.3. Representations of doctor-patient relationships

One of the main themes identified during the netnography contained conversations about the medical professionals, and how the patients interpreted their behaviour and medical competence – in short, their

interpretations of the doctor-patient relationship. Overall, it can be stated that patient accounts show the omnipotence of doctors and medical professionals is fading and that the trust of the patients towards them is questioned quite often- During the analysis of doubts and distrust, a distinction was made between the intent and the knowledge of the medical professionals. The result supports findings from both international and Hungarian studies (Cavenagh et al., 2013; Molnár et al. 2018; Rózsa, 2016; Vanderminden and Potter, 2010).

- The results from the patient interviews also supported that one of the main influencers of the treatment experience is the relationship between the patients and their caregivers. The tones of the responses were much less heated, showing why combining a passive and an active methodology can be beneficial to explore the wide spectrum of opinions and emotional engagement. It was demonstrated in conversation (even in an environment that was set to be relaxing and open) the patients constrained themselves.
- Changes in the traditionally hierarchical and asymmetrical doctor-patient relationship can be attributed to

- four influencing clusters: (1) closing of information gap; (2) lay expertise; (3) limited trust towards medical professionals; (4) consumer attitude of the patients.
- The role of information, knowledge, and lay expertise proved to be quite influential on the doctor-patient relationship. The influence can be categorized into two main strains, either (1) enhancing cooperative behaviour, or (2) questioning the medical authority. The first type builds up to a more harmonious relationship, grounded in a mutual understanding, while the latter escalates distrust, and may even reduce compliance, careful cooperation can be observed between the two endpoints.
- Besides examining from the viewpoint of the consumer expectations, an integral part of the online debate focused on guesswork about professionals' expertise and skills, and their behavioural motivations from different perspectives.
- The dysfunctions of the doctor-patient relationship that are rooted in distrust may also originate from bad earlier experiences. With the emotional volatility of patients during their treatments, they are much likely to

- project individual bad experiences with medical professionals towards the entire system.
- Most of the extremely negative discussions were concerning the misguided intentions of doctors. Several patient accounts reflected on what they interpreted as money-hungry demeanour from doctors, saying that they would only express interest and kindness to patients who paid them, who were partaking in self-financed treatments. On the other hand, patients who were paying did in fact expect better care than in the state-funded facilities and expected that they be treated as valued consumers by the doctors.
- The findings from both the netnography and the patient interviews illustrate the questioning of the traditional hierarchical relationship, patients want not only to comply to orders but to understand and fully participate in their treatments. These findings resonate with the notions of Mead and Bower (2000), who have in their works advocated for greater patient involvement, granted through adequate and responsible communication.

4.4. Gendered responsibility, the burden of gender

- Women are both socially, on the macro level, and on the micro-level seen as the partner mainly responsible.
 The macro-level originates from pronatalist views and policies of Hungary, and the traditional view of the importance of biologically related children.
- On the micro-level the responsibility is burdened on women partly through their everyday interactions with the infertility specialists (they reinforce the primary role of women through information sharing and treatment practices), and the fact that due to the male-breadwinner type of family dynamics while the potential fathers want to participate, they are unable to take adequate time off from work.
- There was no relevant distinction between patient accounts gathered with the different methodologies.
 Online discussions were more open in discussing the sexual aspect of the relationships, but when directly asked the interview participants did not shy away from the topic either.

- Both the results of the netnography and the interviews support the notion that women and men have different ways of coping with childlessness and the treatments.
 The fact that women are more vocal about the issue is clearly illustrated both by the participants of the online discussion communities and the interviews.
- Male participation in the treatments was more limited, this is due both to the medical nature of the procedures, but also because it was reported that men had difficulty getting time off from work, especially it the couple did not want to share that they are partaking in infertility treatment (the regulation offers special protected status for women who are participating in infertility treatment).
- Male direct participation in treatment can be categorized into three main stages of infertility treatment as reported by the online authors, these are respectively stages of (1) planning; (2) testing; (3) partaking and emotional and physical support throughout treatment.
- It was registered though that in cases the fact that women were much more involved in assuming genetic

- responsibility during assisted reproduction was not at the will of the partners but rooted in the system itself.
- Three specific clusters of instances could be observed: (1) at the clinics the couples were separated, taken to different areas for testing and even for some procedures; (2) men had difficulty getting off from work during the times the tests and procedures were performed; (3) the doctors and the medical staff communicated foremost with the women, even when their partner was present – achieving the feeling that the genetic responsibility laid mainly with the women.

5. Contribution of the thesis

The aspired social scientific contribution of the dissertation can be grabbed from multiple angles. Firstly, with the ambition to expand upon prior domestic and international findings. Albeit public attitude towards medically assisted reproduction is not an under-researched topic domestically, less has been known through the interpretation of patient narratives, via investigating their biological disruptions. Understanding of these experiences led to

identification of problem-hubs that are addressed with policy and communication recommendations in the dissertation.

Secondly, the there was an aim to add to theoretical sociological knowledge by bringing together multiple sociological approaches that have in this fashion not yet been analysed together. The findings of the dissertation thus add both to domestic and international knowledge plethora of STS, medical sociology, gender studies, and online communication inquiries. The theoretical novelty can be found foremost not in settling an overall theoretical debate, but in creating an interdisciplinary juxtaposition as a base for multi-dimensional investigation of an increasingly relevant social phenomenon. In addition, the results of the thesis do contribute to a debate about lay expertise and its acceptance in an ongoing debate about public understanding of science models, providing evidence to support the claims of its existence and societal relevance.

The third major aim of the project was to successfully apply a multimethod approach, combining passive and active research methods within the qualitative paradigm, and

connecting online and offline data. The methodological contribution of the thesis offers a novel way of investigating health and illness but can also be adapted to other relevant social phenomena.

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