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**Narrated Experiences of Medically Assisted
Reproduction in Hungary**

Infertility from a Multimethod Perspective

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Sociology and Communication
Science**

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Ph.D. Thesis

Zsófia Bauer

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1 Introduction

Complex and innovative scientific technologies and controversies surrounding them are the own of modern societies (Brossard and Lewenstein, 2010). To introduce this dissertation, I quote Memmi “*the mid-20th century brought the unprecedented development of biology as a science, allowing for the biotechnological expansion of the self.*” (Memmi, 2015, p. 92). Technological innovations are part of our everyday lives – they can better, or they can invade, but there is no question that technology has become intertwined with our communications, our work, our health, and our overall dispositions and interactions with society. We see this more and more with each day.

The past year that has been marred by a global pandemic has highlighted how dependent our post-modern world is on technology, how fragile our health is, and how the life-changing and life-saving medical technologies have complex and controversial societal and individual perceptions. We have experienced first-hand the development and reception of a significant yet dividing biomedical advancement. In addition, the imminent controversial relevance of our societies’ changing relationship with the medical profession and scientific community has come into focus.

Theoretical frameworks and research explored and presented in this doctoral thesis have been rapidly evolving as the world around us, trying to keep up with medical advances and their everchanging nature, a massive shift towards online communication and opinion dissemination, and a discombobulating mass of narratives about family dynamics, health and illness, medical innovation, technology and ethics, a growing scepticism towards institutional science – the symbolic triumph of lay expertise, and coping with the reality that the world and society we have come to know and understand is fragile and will most likely never be the same again.

Over the past decades a number of social scientific analyses have realized the important connection between technology and social systems and have argued that it is important to study relationships between science and society to gain a deeper understanding of how these fields influence each other (Hornig Priest, 2010). The rise and rapid ground gaining of Science and Technology Studies supports this fact, and the salience of social scientific inquiry of technological advancement, expertise, and the role

they play in society (macro and micro level) is without a doubt going to be one of the most exciting fields of sociological theorizing and empirical research in our near and distant future.

Already we can see that more and more research projects are investigating questions of how science and society mutually form the other. Over the last decades large number of high-profile scientific journals, courses and specializations offered in the specific field have become a core part of social scientific inquiry. However, compared to Western European countries and the Anglocentric countries, the investigation of science and technology from a social scientific perspective is present in Hungary only to a lesser extent (Inzelt, 2010). Several research projects have thus aimed to fill this gap, and the trend shows a growing interest in technology studies, STS, sociology of innovation alongside investigating the ethical and moral dilemmas related to these. This dissertation is embedded in this recently emerging Hungarian interest and hopes to provide relevant insights both at home and on an international level.

As of the time of writing this thesis, approaches combining a Science and Technology Studies (STS) perspective with a sociological focus and investigating medical and biotechnological innovations were scarcely present within the social scientific community of Hungary. More and more studies are conducted as of now, and the Covid-19 pandemic surely escalated the interest of sociological inquiry.

Some relevant exceptions addressing the societal impacts of technology from a multi-dimensional theoretical perspective include studies concerning stem cell research and genetically modified foods, the role of artificial intelligence in human interactions, communication technology and our OTKA funded research project on assisted reproductive technologies (Infertility And The Socio-Technical Practice Of Assisted Reproductive Technologies) headed by my tutor Lilla Vicsek and encompassing my study. The research foundation of this thesis aims to investigate experiences and perceptions of medically assisted reproductive technologies applying several distinct theoretical approaches and working with a multimethod research design.

In the world of natural sciences, the topic of reproductive technologies has been a popular question and research interest for decades now. Even if one attempts only a birdseye view of the field, it is noticeable what an enormous corpus of medical literature

has accumulated in the last few decades. The advances in biotechnology have also become special and influential topics of research in both natural and social sciences. There has been a myriad of research trends dealing with human reproduction and society, investigating the topic from several angles, which are by and large too numerous to list here (e.g., feminist perspective (Doyal, 1987; Franklin, 1995; Becker, 2000), technology oriented (Lambert and Rose, 1996; Irwin and Wynne, 1996; Hudson et al., 2009), or from the viewpoint of bioethics (Memmi, 2003; 2015)).

In the Hungarian social scientific community until recently, assisted reproduction was mainly looked at from a demographic, legal or psychological perspective (Cserepes et al., 2013; 2014; Kapitány and Spéder, 2019; Keglovics, 2015; Sándor, 2005). More recently there have been sociological projects investigating the public attitudes concerning assisted reproductive technologies, analysing large databases, using statistical analysis (Szalma, 2014; Szalma and Bitó, 2021), or qualitative methods (e.g., Vicsek, 2018, Szalma, 2021a, 2021b). The lived experiences of patients utilizing the technologies were studied in-depth applying several methodologies, guided by multiple theoretical fields by Vicsek and research team, including the author of this doctoral dissertation. Novelty of this cluster of inquiries was seeking inspiration from diverse fields such as science and technology studies, bioethics, medical sociology and media and communication studies.

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). 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 also 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 by the Hungarian sociological community. Moreover, 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.

One aim of the research is to help accelerate the slowly, but steadily growing body of Hungarian sociological inquiry on assisted reproduction using theories from both traditional sociology and science and technology studies. Another goal is to broaden the spectrum of methodologies investigating the topic by applying a multimethod approach based on both active and passive research methods. By combining netnography and qualitative interviews, the project not only introduces a novel methodological solution to study medically assisted reproduction, but also promotes the broader use of netnography in the Hungarian sociologist community.

In accordance with these goals, the primarily exploratory research project aims to broaden, reassess, and significantly deepen our knowledge and understanding about infertility treatments foremost through the in-depth and rich analysis of the experiences and constructions of infertile patients within the different branches of the Hungarian health care system. As such, on the one hand the research will be investigating the factors influencing the use of medically assisted reproduction, on the other hand it will also examine those experiences the patients have during their treatment within the healthcare system. My research focuses on patients, viewing infertility from the medicalized perspective foremost since some research questions were formulated to gain insight into infertility treatment in the medical context, with special focus on the doctor-patient relationship. This understanding can bring forth those elements of the treatment that are working well (as lived by the patients), but also pinpoint those processes and experiences that show discrepancies in the views of the patients. It also aims to understand how factors behind the changing doctor-patient relationship (such as lay expertise, informed consent) are present in everyday practice of medically assisted reproduction.

The social scientific contribution of the dissertation and grounding thesis research can be grasped from a thematic, theoretical, and methodological angle. On the one hand the thesis contributes to the body of Hungarian knowledge about infertility and medically assisted reproduction, by examining those patients' perspectives who have partaken in

treatment. The empirical findings of the thesis aim to expand upon prior research by adding to the understanding of this unique population, and how their experiences are impacted by firstly, the pronatalist rhetoric and social policy of the Hungarian government and secondly the specificities and disfunctions of both the public and private branch of our health care system.

On the other hand, examining the contributions from a theoretical perspective, the innovative nature of the dissertation lays in the purposeful interlacing of diverse branches of social scientific inquiry. As could be seen in earlier paragraphs, medically assisted reproduction is not an under-researched topic on the international level, but the technology and its recipients. the patients are mostly researched from distinct, isolated sociological fields. My doctoral dissertation has identified this gap and has aimed to bring together a handful of sociological approaches to create a unique framework for the thesis research.

The biographical disruption and their lived experiences are investigated through a novel combination of theoretical considerations, the research brings together four distinct fields of sociological inquiry that are typically not analysed together. The findings of the dissertation thus adds both to domestic and international knowledge plethora of STS, medical sociology, gender studies and online communication inquiries. The theoretical novelty can be found 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. The thesis does provide further empirical evidence for the arguments of the contextual element of lay knowledge and the existence of lay expertise, which has been a longstanding debate of the public understanding of science strand of science and technology studies. The dissertation argues for the acceptance of the theoretical and empirical concept of lay expertise and the relevance of lay expert patients influencing interaction between professionals and patients.

Lastly impact of the thesis can be identified within its applied multimethod qualitative research design. Netnographic analysis is relatively new in social scientific investigation (especially in Hungary), which on its own merits allows for new research traditions to gain roots in the Hungarian sociological community. In addition to the use of an innovative research method, the methodological design also introduces a way to combine the analysis of online and offline data, which can also contribute to international

methodological literature.

The dissertation is structured as follows: First it introduces the core concepts used in the thesis from both the social scientific and the medical realms. Then the chapters continue to address theoretical questions by discussing the model of the theoretical approaches of the thesis which combines theories from four distinct fields: science and technology studies, medical sociology, gender role theory and online communication works. A focused introduction of relevant empirical literature follows. The research is given cultural and societal perspectives by introducing to detail its Hungarian context, along with the empirical findings of Hungary related inquiries, before detailing the research questions embedded in the above traditions and contexts.

The subsequent chapter introduces the applied methodologies. It dives deep into the explanation of the qualitative and multimethod research traditions, before giving a comprehensive introduction to the lesser embedded netnographic methodology. The section provides details about qualitative patient and expert interviews as well.

The exploration of the results and subsequent analysis of the findings follows the order of the presented research questions, each question relying on core aspects of one of the applied theoretical approaches. The analysis investigates the main themes narrated by the patients, the concept of lay expertise, intertwined with the changes occurring in the doctor-patient relationship, and finishes with a focus on the concepts and portrayal of gendered reproductive and genetic responsibility. The findings show that relevant new insights can be unveiled, and the patients using medically assisted reproductive technologies can be understood in greater depth by applying new combined theoretical frameworks alongside a multimethod approach applying a relatively novel method in the Hungarian social scientific scene.

The dissertation continues with the introduction of the limitations of the thesis research which help pinpoint opportunities for further inquiry. The work closes with a number of research based professional and policy recommendations that serve to highlight problematic areas for stakeholders and subsequently better the experience of medically assisted reproduction.

2 Background, concepts, and definitions of the thesis

The following chapters of the thesis aim to provide a structured overview of the social and medical concepts, theoretical approaches and empirical results that have inspired and influenced the study. Firstly, this section is dedicated to identifying core social and medical definitions applied throughout the course of the research and the pages of the dissertation.

This chapter helps to clarify the meaning of reoccurring concepts used during the dissertation. Introducing medical and pharmaceutical definitions in social scientific thesis may seem unusual at first glance (perhaps more to those who have yet to dive deep into STS or medical sociology) but is necessary for the purpose of explaining and underpinning the scope of the study, and setting the guiding principles for the recruitment of the cluster of interview participants and mark the way the online conversational data was isolated. Introduction of these definitions is structured as a funnel, aiming to introduce the different definitions from the widest moving on to the narrower specifications.

2.1. Definitions of involuntary childlessness and infertility

The first concepts that shall be clarified are ones of involuntary childlessness and infertility. The former of the two is the broader concept, dealing with issues that are more divergent – this concept is broader than the medical definition that was applied throughout the research.

Childlessness can be viewed as a state when due to diverging factors the individuals did not have children throughout their life-course. The literature makes a clear distinction between voluntary (or childfree) and involuntary childlessness (Szalma and Takács, 2012; 2018).

Involuntary childlessness is to be distinguished from childlessness according to the underlying factors that have led to the state of the individual or couple not having children. Within involuntary childlessness it is also necessary to make a distinction of those who are involuntarily childless due to biological problems and other factors.

Throughout my project I will reflect on those who have conception problems due to these biological problems. The participants in the interview prong of the OTKA research and the online discussion comments analysed in the netnography of the dissertation are dealing with infertility and medically assisted reproduction – the participants were recruited amongst women, who had received treatment, or were in the process of receiving medical assistance. The conversations streams were also isolated with a selection-criteria that aimed to find forum threads with content creators who were medical patients.

The research built on the concept of *infertility*, that according to the wide-spread medical definition of the term as the *failure of a couple to conceive after trying to reach pregnancy for at least one year of regular unprotected sexual intercourse* (HCOG, 2012; MHCH, 2019). According to a 2012 clinical protocol issued by the Hungarian College of Obstetricians and Gynaecologists, 10-15 percent of the couples who are trying to conceive can be estimated to be infertile in Hungary, being diagnosed as infertile at the end of a rigorous examination and evaluation process that has a very clear and distinct protocol to be followed by the medical professionals (HCOG, 2012). This statistic was modified in 2019, showing a significant escalation – stating that the problem of infertility effects 15-20% of couples trying to conceive (MHCH, 2019). This modification shows directly how decline in fertility due to medical reasons is rising, along with the demand for medically assisted reproduction procedures.

Another key concept for those partaking in medically assisted reproduction is *subfertility*, which is decreased fertility, where pregnancy is reached in the course of one year, but with difficulty (MHCH, 2019).

2.2. Definitions of RT, MAR and ART

Reproductive technology (RT) can be defined as uses of technology in human and animal reproduction. Human reproductive technologies can be identified as uses of technology during the course of human reproduction, during which the treatment selected will be in accordance with the problem of the couple (ESHRE, 2020; Hudson et al. 2009).

The International Committee for Monitoring Assisted Reproductive Technology (ICMART) and the World Health Organization (WHO) have suggested the following

definition for *medically assisted reproduction* (MAR): “reproduction brought about through ovulation induction, controlled ovarian stimulation, ovulation triggering, ART procedures, and intrauterine, intracervical, and intravaginal insemination with semen of husband/partner or donor” (Zegers- Hochchild, 2009, p. 1523).

Assisted reproductive technologies (ART) can be defined as: “all treatments or procedures that include the *in vitro* handling of both human oocytes and sperm or of embryos for the purpose of establishing a pregnancy. This includes, but is not limited to, *in vitro* fertilization and embryo transfer, gamete intrafallopian transfer, zygote intrafallopian transfer, tubal embryo transfer, gamete and embryo cryopreservation, oocyte and embryo donation, and gestational surrogacy. ART does not include assisted insemination (artificial insemination) using sperm from either a woman’s partner or a sperm donor” (Zegers- Hochchild, 2009, p. 1521).

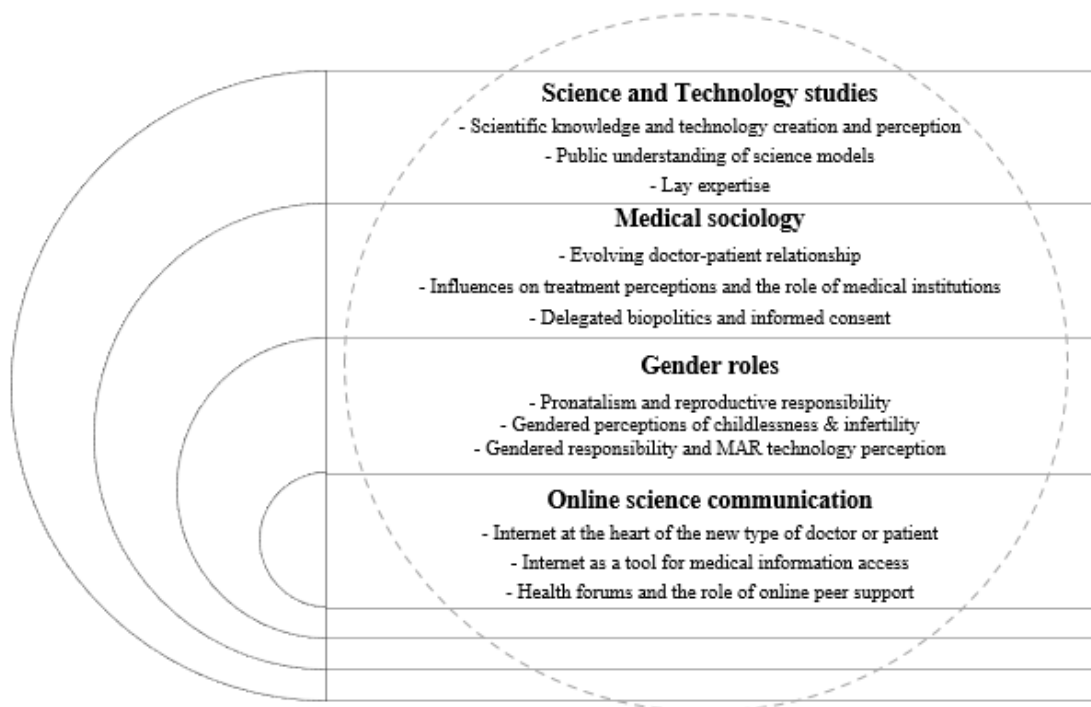
The 2012 and 2019 Hungarian protocols also suggest that patients diagnosed with infertility are treated with a wide array of medically assisted reproductive technologies. In vitro fertilization (IVF) is the treatment that is at the focus of public perceptions, but most infertile couples have gotten help through or have explored a myriad of other medical options available to them before IVF cycles, but the number of patients waiting for treatments is escalating¹ (MCHC, 2019).

¹ The research does not touch upon how the Covid-19 pandemic has affected the availability of MAR and ART in Hungary. The reason for this is that while the writing of the thesis takes place during the pandemic, the data collection was prior. The author of the thesis has an ongoing inquiry into how the corona virus has affected the availability of other health care treatments – but only preliminary results are ready. Early findings suggest that MAR and especially IVF cycles have been postponed, and even cancelled. The effects of vaccinations have not yet been analysed.

3 The theoretical approaches of the thesis

3.1. Model of the theoretical approaches applied in the dissertation

This section aims to provide an overview of theories from the different research fields that are connected to the research topic and serve as foundation and inspirational guide for the thesis. The complex theoretical framework and core questions and concepts are modelled and summarized in Figure 1. The foundation of the thesis can be traced to intersections of four major research fields and deploys knowledge as depicted in the model below.



1. Figure: The theoretical frameworks of the dissertation

On the following pages first, I will give a short contextual introduction of the wide field of Science and Technology Studies (STS) as perhaps this line of societal inquiry has the least exposure in the Hungarian social scientific community. After a birdseye view of this plethora of knowledge, I will turn my attention towards a narrower framework within STS, focusing the literature review to public understanding of science and scientific

topics (PUS/PUST) and introduce the concept of 'lay expertise'. The chapters give a more in-depth and detailed overview of the science communication models developed and elaborated to explain the public understandings of specific scientific, namely medically assisted reproductive technologies.

In the subsequent portion of the theoretical overview, I acquaint the reader with relevant literature from medical sociology to investigate changes in the doctor-patient relationship. The link between medical sociology and STS will be introducing concepts of delegated biopolitics and informed consent to make a connection between public understanding of science, lay knowledge and the deconstruction of the formal hierarchy between medical professionals and their patients. This will be linked to online science communication models, by examining the role of internet in knowledge gathering and dissemination, and the function of online health forums and other public channels in the web-sphere.

Specific relevant concepts from gender role theory and pronatalism will be explained, as public perceptions and lay understandings of childlessness, infertility and medically assisted reproductive technologies are heavily influenced by gender roles, and the decisions and participation in the assisted reproduction patient pathway is also affected by the patients' gender.

The last of the theoretical chapters will deal with online communication and the role of the internet in communication on health and patient well-being. While the section focuses on the role of the online sphere mainly from the patients' viewpoints, it also grazes the surface of linking their needs to professional communication.

3.2. Approaches from science and technology studies

3.2.1. Introduction of the chapter

Science and technology studies (STS) (or in some interpretations and sociological terminology Science Technology and Society) is a thriving and maturing field of research within social science (Bijker and Callon, 2008; Szabari, 2008). STS deals with a wide range of topics, adopting numerous concepts and theorem, and authors concede that there is no single sociology of science (Bucchi, 2004; Rohracher, 2015). “*Science and Technology Studies (STS) starts from an assumption that science and technology are thoroughly social activities*” (Sismondo, 2010, p. 11). Thus, STS takes on questions of how social, political, ideological, economical, and cultural values can influence scientific processes and knowledge production, and in turn how the scientific world can affect society, politics, and culture.

The evolution of social scientific thinking in the last few decades have made science, technology, and innovation practically inseparable from the field of sociology and science and technology studies, making the approach highly relevant and popularly current. As there is no static interpretation of science or technology, along with their influential role in shaping society, there is no one identifiable, mainstream prong within STS. Examining the field, we must conclude that there is a bounteous number of mutually non-exclusive theoretical and empirical research conducted, examining a vast array of topics and social phenomena. The important focal point of these is the junction of social and natural sciences (Király, 2005).

Indeed, the international corpus of literature agrees that STS is a highly diverse field with an interdisciplinary nature and STS has been splintering the strict boundaries across disciplines, adopting theoretical thinking, methodological approaches (Bauchspies, Croissant and Restivo, 2005; Giacomelli and Giacomelli, 2005). STS is by its nature interdisciplinary and everchanging evolutionary (Sismondo, 2010). Scholars of science and technology studies maintain a close relationship and dialogue with philosophers and historians of science, natural scientists, anthropologists, ethicists etc. All forementioned approaches and paradigms contributing to the abundant and at times

discombobulating plethora of science and technology studies driven understanding (Bucchi, 2004).

Keeping this impression in mind, we must acknowledge that it is difficult, most likely impossible to take inventory of all the topics, theoretical frameworks, ideological guidelines, and methods in a dissertation literature review. Therefore, in this section of the dissertation I will give only a quite brief overview of the historically salient, at times revolutionary directions within STS. The chapter will not attempt to enumerate and introduce all aspects and angles of STS, after the panoramic overview I will focus and dive deeper into those directions and approaches that have yielded results significant for my research. Therefore, after taking a more detailed look at the complex interpretations of public understanding of science, the theoretical introduction will turn to examining the role of lay knowledge and expertise.

3.2.2. A birdseye view of STS – interpretation of science and technology through a social lens

On the one hand the international literature agrees that interest in science and especially technology is a late bloomer within the scope of sociological inquiry (Bucchi, 2004; Giacomelli and Giacomelli, 2005; Rohracher, 2015; Sismondo, 2010; Yearly, 2005). On the other hand, most authors would concur that by now there is an inherent mutual interdependence of technology and society (and their examinations), as technologies can be interpreted as material products of human social activities (Bauchspies, Croissant and Restivo, 2005, p. 9), their study is by the 21st century a mature field of social scientific research. Jasanoff (2010) explains the emergence of interdisciplinary STS with the fact that other disciplines neglect to study the inseparability of science and technology from society (social structures and practices). STS has since then been influenced and intertwined with sociology, philosophy, political science, and economics (Rohracher, 2015).

This interaction between science and society has been labelled with the phrases technosocial or sociotechnical, and STS operates under the assumption that science and technology are to be interpreted as intertwined with the social and political sphere (technoscience) (Sismondo, 2010; Woodhouse, 2005; Yearly, 2005). Drawing from the interpretations of Bauchspies, Croissant and Restivo (2005, p. 9) the term “technosocial” is used to describe the “mutual interpenetration of technology and society”, highlighting

“how technology affects social relationships, how social relationships affect technology, and how this changes over time and place”. This statement, which may seem self-evident within the sociological communities of the 21st century was not always the case throughout STS’s short but complex history.

According to Latour (1992) the products of science and technology, while in fact bonding the social world, were largely unnoticed by sociologists for quite a while. This oblivion is constituting to what he calls ‘missing masses’. Literature points out how one of the identified reasons for such late coming interest in the topic draws on the following notion:

For a substantial period, it was assumed that the world of science was so exceptional and so independent, that it was governed solely by its own principles, and had little meeting points with majority society. As Yearly eloquently put it: ‘the special character of science’ (Yearly, 2005, p. 1) got in the way of sociological inquiry.

This traditional interpretation of science and technology basically assumed that scientists could produce the same knowledge and deliver uniformed results independent to their social and political contexts. It was depicted as if scientist were operating in a ‘black box’ which was inaccessible and incomprehensible to laymen and therefore there was no contesting the scientific community’s overarching consensus about the truth (Bucchi, 2004).

This uniformed, and by today’s understanding rather simplistic view was gradually abandoned as science became one of the most dominant social, political and economic factors in the second half of the 20th century (Sismondo, 2010). Theoretical and methodological experts adopted a more complex, nuanced approach and claimed that there is not one distinct scientific method. They claimed that contemporary (and also historic) scientific activity is heavily influenced by the social and the political fields, its complex circumstances (Yearly, 2005). Moreover, according to Bauchspies, Croissant and Restivo (2005) science and technology are to be interpreted as social relations, which is to say, they should be viewed as socially constructed. Social processes and contexts should be afforded attention, as these are structures in which “scientists organize and give meaning to their observations” (Bauchspies, Croissant and Restivo, 2005, p. 24).

While the topic of science and technology may have entered at a considerably late

period in the history of sociology, in the past few decades' sociologists have become increasingly interested in the relationship between society and science and technological innovation. This change is underpinned by the fact that science and technologies are often at the focal point of public and many times ideological-political debates. This is especially the case with so-called controversial technologies (i.e., atomic energy and advances in biotechnology / biomedicine)².

This elevated interest led to the sociology of science becoming a field with highly diversified areas of research, resulting in a massive amount of empirical evidence that often fuel debate not only within the scientific, but also in a broader community (Bucchi, 2004; Bauchspies, Croissant and Restivo, 2005). Key disciplinary elements of STS have continually evolved since the sixties and keep on changing continuously. During this evolution there has been some debate about whether science and technology studies is even part of sociological inquiry. This dissertation is in line with the strand of thinking that emphasizes that despite being vocally interdisciplinary, STS has deep roots and is deeply embedded in the sociological tradition.

When examining the history of STS, the publication of Thomas Kuhn's *The Structure of Scientific Revolution* (1962) was ground-breaking. In this work Kuhn highlights the impact of society on shifts in scientific paradigms (which he classifies as a type of 'struggle'), and thus on the evolution of scientific knowledge itself. Science does not accumulate knowledge straightforward, but "instead moves from one more or less adequate paradigm to another" (Sismondo, 2010, p. 16) – "changes in theories are not driven by data but by changes in vision" (Sismondo 2010, p. 21). Some consider Kuhn's work to be ground zero for developing the discipline of STS (Bucchi, 2004; Sismondo, 2010; Yearly, 2005).

From the field of sociological inquiry one of the forerunners of the sociology of science was the classical theorist Robert K. Merton, who was one of the first sociologists to make inquiries into the realm of scientific knowledge and its production. Merton (1968, 1973) and students (Zuckerman and Merton, 1971) investigated how the scientific community functioned – how it was structured. According to Bucchi, Merton is to be

² Escalated social and political debate can be observed about Covid-19 vaccinations, social perceptions about this biomedical advancement although is not the topic of this doctoral thesis, is part of the authors new research projects (Bauer, 2021b; Bauer and Koltai, 2021).

considered ‘the founder of this sector of sociology’ (Bucchi, 2004, p. 14).

Merton (1973) detected that scientific activity in his time was neglectfully considered entirely different from other social phenomena and proposed that the realm of science/scientific actions be subject to the same sociological inquiry as are other social issues. Merton’s functionalist notion of connecting science and knowledge to the social world was crucial in the grounding and forming of the discipline. Merton’s work contributes to studying the interconnectedness of science and society in the following three ways according to Rohracher (2015). Firstly, Merton recognized that development of social surroundings influences scientific knowledge and community; secondly the scientific community operates according to its own distinctive normative order (‘special ethos of science’); thirdly how the before mentioned normative order is upheld by the practices and rewards within the scientific community (‘Matthew effect’).

While acknowledging Merton (and colleagues) as a founder of the field in investigating scientific conduct (his work on the Matthew effect still has significant influence though), his critics mention that his perspective idealized science and scientific organizations – claiming that science and democracy were mutually good for the other (Bauchspies, Croissant and Restivo, 2005; Sismondo, 2010).

Yet as mentioned earlier, at the time science and scientists were almost abstractly untouchable by critique, and expertise was regarded with an aura of unconditional respect – ‘ethos of science’. This technological progressivism and technological determinism were grounded in the ideas that science is inherently good and is always a crystallization of progress, serving public interest and being a benefit to society as a whole. There are still views stating that technological development has solely benefits, “leading to economic progress and increase in well-being” (Giacomelli and Giacomelli, 2005, p. 2). Talcott Parsons (1951, 1968) was vehemently criticized from a similar perspective on his functionalist approach to the physician-patient relationship. The approaches and framework of Parsons are detailed in a subsequent chapter of the dissertation, where concepts of medical sociology are introduced, that serve as the second prong of the theoretical approaches and inspirations.

STS as an independent field emerged in the late seventies, early eighties – and had two distinct set of approaches, connected with the common focus to understand the

“social fabrication of scientific facts” (Rohracher, 2015, p. 202). In both cases the locus of investigation was natural sciences – first focused on sociology of scientific knowledge, while the other dealt with ethnographic studies involving laboratories and the scientific knowledge production in these unique settings.

Firstly, looking forward on the path of connecting the fields of science and social thought, one of the most influential thinkers within STS David Bloor (1984) was an advocate of the ‘strong programme’ and a scholar of the Edinburgh school. Their focus of study was ‘sociology of scientific knowledge’ (SSK) and theorized that scientific knowledge is very much a product of its originating culture and procured by social influences (factors outside of the scientific community), and thus found it extremely important to study the practices of scientists when producing this knowledge (Bucchi, 2004). The strong program was again a step away from the traditional ‘black box’ view of science and technology introduced earlier.

Another group of researchers also looking at scientific knowledge generation focused more on discourses and scientific controversies, and the inner functioning of knowledge production. EPOR or ‘empirical programme of relativism’ was headed among others by Harry Collins and Trevor Pinch connected to the University of Bath (Rohracher, 2015). While the “strong program” only advocated that societal facts/cultural context – macrosocial phenomena – have an influence scientific knowledge, scholars conducting so-called laboratory studies claimed (Latour and Woolgar, 1979; Knorr-Cetina, 1995) that individual knowledge production sites also have peculiar effects that are to be studied and interpreted on a micro-sociological level. These mainly ethnographic laboratory studies bring into focus both the formal and informal processes in the construction of scientific knowledge. These laboratory studies focused foremost on natural scientific contexts.³ Critics claimed that this type of inquiry neglected the consideration of the broader social context (Bucchi, 2004; Rohracher, 2015).

Actor-network theorists (Latour (1987), Callon (1986), Law (1987)) in addition take into account the full spectrum of actors within the construction process, elevating both human and non-human actors and entities into their focus. These different actors are

³ Laboratory observation was one of the methods utilized in our OTKA funded research, for details see Vicsek, Király and Kónya (2016).

attributed agency and affect each other, symmetrical along the human and non-human divide. ANT scholars' studies deal with concrete actors and do not focus on macro-level influences, creating a general theory that explains the centrality of science and technology to the idea of modernity (Sismondo, 2010, p. 85 based on Latour, 1993). The concept of technoscience is introduced, studying the practice of heterogeneous networks from a materialist perspective (Rohracher, 2015; Sismondo, 2010). Critics have noted that one problem lays within the aforementioned symmetry, supposing that all agents and groups were awarded the same level of influence in this model (Bucchi, 2004), but at the same time others criticize that ANT analyses downplay the role of non-human actors, being that the humans "are more interesting" (Sismondo, 2010, p. 90).

Another line of STS was shifting focus from scientific knowledge to technology itself⁴. This was a decisive time in the development of STS. Pinch and Bijker (1984; 1987; 1990) formulated the framework 'social construction of technology' (SCOT) for a framework for thinking about the development of technologies. Within this framework they attempt to identify actors and agents that are relevant in the innovation process of a new technological artifact, applying the methodological aspects of earlier introduced EPOR. Technologies in their view are subject to different interpretations ("interpretative flexibility") and development is not linear, very much under the influence of social contexts (Rohracher, 2015) success of artifacts depend on the strength and weight of the social group promoting them (Sismondo, 2010, p. 99). Social constructions are created by interactions, which can change perceptions (Woodhouse, 2005). According to Sismondo (2010, p. 57) social constructivism indicates three assumptions: science and technology are social, they are active, and their products are not themselves natural. This interpretative flexibility reveals the trajectories of technologies and the relevant social groups framing them.

After these core lines of STS developed interest of the field turned towards questions of expertise, credibility with an intense focus on the relationship between science and policy – introducing a new research interest in those who do not partake in knowledge production, but have experiences with technologies (Sismondo, 2010, Rohracher, 2015).

⁴ Critics argue that focus on technology within STS is downplayed (Sismondo, 2010).

The third wave of science and technology studies which Collins and Evans (2002) call Studies of Expertise and Experience (SEE) places the question of different types of expertise and participation in decision making in the centre for of inquiry. They open their inquiries towards who are not official producers of scientific knowledge. In their work they rely some extent on previous studies regarding expertise within the non-scientific community (in particular writings of Brian Wynne) that will be introduced in the subsequent part of the chapter.

This newly emerged focus is rather policy driven, central interest being who should legitimately participate in decision making (Rohracher, 2015). A more meaningful conversation between actors must be achieved according to Jasanoff (2010) and innovation must be coupled with adequate participation⁵.

3.2.3. Focusing in: Science and the layman

As Brossard and Lewenstein (2010, p. 11) argue science has become an inherent aspect of modern societies, and thus is in constant relation with the public. Yet centuries of history showed professionalisation and institutialization that systematically led to the separation from laypeople until second half of the 20th century (Gregory and Lock, 2008).

The last decades show different tendencies and the public in turn has the chance to form an opinion on the subject and in democratic societies have public debates that in fact influence policy making regarding controversial scientific issues and technologies. Media and media representation plays a significant role in both dissemination of ideas and influencing public opinion through agenda setting and framing (Sismondo, 2010). The dominant model or diffusionist model have been coined to illustrate how science popularization works (Bucchi, 2008; Lewenstein, 1992). At the focal point of this model is the knowledge gap between producers of science and the receiving public, making it necessary for mediators to join in the interpretation. These conduits have been criticized for distortion: oversimplifying and juvenilizing the public – applying the deficit model of public understanding of science (Bucchi, 1998; 2013; Wynne, 1992). The dominant model

⁵ Public awareness, participation, and transparency of technology - concepts of Jasanoff are becoming even more important with the Covid-19 pandemic - as the trust in experts show radical erosion and anti-science movements gain ground in the form of disinformation in the online sphere (Bonnievie et al., 2020; Tagliabue, Galassi and Mariani, 2020).

assumes that scientific knowledge is not connected or shaped by context.

While the ‘strong program’ and especially Bloor (1984) advocated the importance of cultural influence and laboratory studies focused on certain micro-sociological processes within the knowledge creation process, for a long part of its history STS research neglected the non-scientific component of society, namely the lay public.

Laymen encounter science and especially technology on a day-to-day basis yet only late in the 1980-s did the connection between the public and science become a topic of rigorous research. At that point major motivator for this strand of STS research was decline in the trust towards science and scientists. The phenomenon was part of general tendencies that were experienced in the decrease of public acceptance and trust in institutions and expertise (Giddens, 1992)⁶. The earlier adopted popular notion of scientific ethos and the belief that scientific achievements and discoveries served only the purpose of a ‘common good’ came into question (Yearly, 2005), and STS scholars turned to investigating public science perceptions.

The main prong of these inquiries has been dubbed public understanding of science or public understanding of science and technology (PUS or PUST). Public understanding of science or PUS is defined as the following: “understanding of scientific matters by non-experts” (House of Lords’ Science and Society report quoted by Burns, Connor and Stocklmayer, 2003, p. 187). Based on a seminal article by Miller (2001) PUS has three elements of definition: (1). Understanding of science content, or substantive scientific knowledge (known as content).; (2) Understanding of the methods of enquiry (so-called process).; (3) Understanding of science as a social enterprise.” (Awareness of the impact of science on individuals and society)” (quoted by Burns, Connor and Stocklmayer, 2003, p. 187).

Research related to PUS is almost as diverse as STS itself. PUS is a relatively new field in STS research with dual aim – (1) to improve the public’s understanding, while (2) exploring the interactions between science and the public (Brossard and Lewenstein 2010). According to Yearly (2005, p. 116) three main research topic hubs can be identified within the scope of PUS: (1) ‘the extent of public knowledge/ignorance of

⁶ This train of theoretical thought will be introduced in greater detail in the medical sociology related chapter of the dissertation.

science and technology'; (2) most effective ways of communicating on these matters; (3) the ways public thought and attitudes about the issues at hand. At times PUS is used interchangeably, as a synonym for science communication, public awareness of science (PAS), scientific culture (SC) or scientific literacy (SL) (Burns, Connor and Stocklmayer, 2003).

The questions above were investigated with several different methods, leading to the description of PUS models described in detail in the next section. Firstly, the traditional survey research in the field of science and technology dealt with measuring the level of scientific literacy amongst laymen. As the evidence suggested the research mainly resulted in conclusions of shocking levels of public scientific illiteracy. Most of these studies were guided by the assumptions and implications of the deficit model of the public understanding of science.

Later in the history of STS inquiry the methodology of these large-scale research was questioned. Subsequent qualitative investigations presented a more nuanced portrait and showed that the situation was not as desperate as priorly claimed. The interested shifted to research exploring relationships between scientists and laymen and institutions (Bauer and Gregory, 2007; Gregory and Lock, 2008). Famous studies include Lambert and Rose (1996), Wynne (1991,1992) and Yearly (1996).

One of the main criticisms towards these survey research was that they looked at 'context-free science', yet people rely on scientific knowledge in a 'context-sensitive way' (Yearly, 2005, p. 120). Indeed, according to Bucchi (2004) there are some particular topics that the public has a quite sophisticated level of understanding and knowledge. According to Wynne who is an active opponent of the deficit driven thinking of PUS/PUST other factors than tacit scientific knowledge must be taken into consideration as well (Wynne 1991; 1992a; 1992b 1995; 2008). Deriving his theory from empirical case studies Wynne turned away from the realist approach of the deficit model to design and apply a more constructivist approach to examining of the public's understanding of scientific issues. In his analysis Wynne and colleagues implied that while their knowledge is different from that of the experts (as it is based on direct and everyday experiences- (Bucchi, 2004)) they are not to be shunned and should definitely be taken into consideration.

3.2.3.1. Public understanding of science models

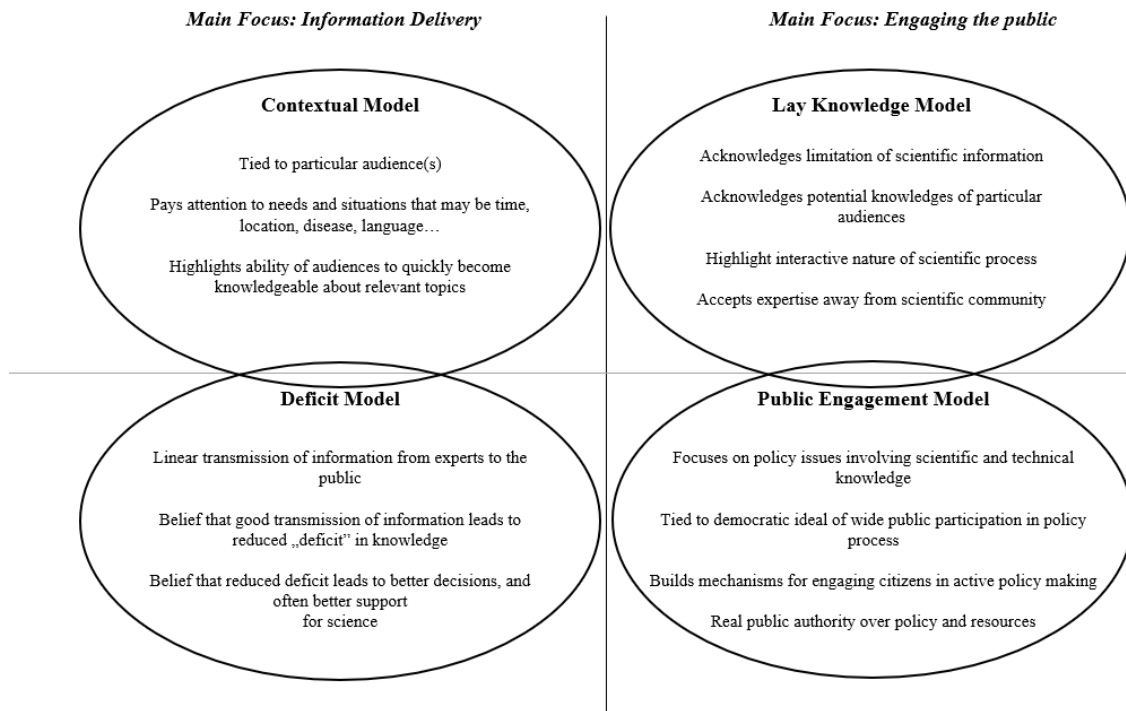
As introduced in the previous section one of the important research topics within the scope of science and technology studies today inquiries into public perception of scientific achievement and knowledge (Brossard and Lewenstein, 2010).

These theoretical and empirical investigations have been branded the label: public understanding of science and technology (PUS/PUST), yet as we could see in the previous section the meaning of this term had several variations throughout the discipline's brief history.

In the past decades several models have been designed for better understanding between the public and the scientific sphere, focusing on both the technology itself and the actors who come into contact with it (Bauer, 2008). Over time new concepts have emerged in the theoretical realm with different focuses.

Brossard and Lewenstein (2010) differentiate four different types of models of public understanding of science: (1) deficit model; (2) contextual model; (3) lay expertise model; and (4) public engagement model.

The models have moved from emphasizing deficit, to models stressing lay expertise, to public engagement and public participation (Brossard and Lewenstein, 2010, p. 11). Stilgoe, Lock and Wilsdon (2014, p. 5) describe the transition as from “deficit to dialogue” and in their view the PUS conversation has “dynamics of change and continuity”. It is important to note that the trajectory of utilizing these models is not linear, and that studies applying the different frameworks of understanding can be conducted at the same time, only driven by different background (Bauer and Gregory, 2007). Theoretical works on PUS models suggest that researchers must consider “the permeable boundaries between models and practice” (Dunwoody, 2010, p. 2). Many current science communication research still focus on the knowledge gap, applying the deficit model (Dunwoody, 2010; Nichols, 2019) – moreover, recent developments of the Covid-19 pandemic have highlighted low science literacy and limited public understandings of scientific development (Bauer and Koltai, 2021).



2. Figure: Conceptual Models of Public Communication of Science and Technology based on Brossard and Lewenstein (2010, p. 17.)

But let us shift our focus back to the introduction and description of the PUS models. Originally questions and debates about public understanding of science were the focus of the scientific community itself, when support for scientific progress and discovery declined (Brossard and Lewenstein, 2010, p. 11). The main producers of scientific knowledge wanted to understand the reasons and mechanisms behind the rejection of the prior unquestioned scientific ethos and started from the assumption originated from lack of knowledge or public ignorance. The early mainly quantitative, large sample survey research were based on the first dominant model in PUS/PUST, that was coined the *deficit model*. The traditional deficit model mainly focuses on the lack of knowledge regarding scientific topics in the public sphere. It also emphasizes the cleavages and information gaps that occur between scientists and laymen – the public is proved to be deficient in knowledge (Bucchi, 2004; Sismondo, 2010).

Science and technological innovation in this model are seen as misinterpreted by the laymen and thus the reactions are deemed irrational. “Overall, the most important finding of the research program is that “science” is not a well-bounded, coherent thing,

capable of being more or less “understood” (Ziman, 1991, p. 100). The forementioned deficit in knowledge and lack of rational interpretation are presented as moral and political problems that need to be corrected through knowledge transfer via systematic education and controlled information supply (Sismondo, 2010). Proponents of the deficit model believe that if the “deficit is fixed” and the knowledge gap is filled then “everything will be better”, science and scientists will reclaim their privileged position (Ziman, 1991).

According to scholars belonging to this strand of PUS thinking, negative attitude is fuelled by ignorance and thus the sophistication and education of the public can lead not only to the decrease in the knowledge gap and ignorance, but to a more positive and accepting attitude towards science without questioning interests and negative motivators (Bucchi, 2008). Others see these mechanisms in greater complexity. Bucchi (2008) claims that this is one of the main aspects of the public’s negative attitudes and distrust (Yearly, 2005) and not only a “knowledge and education problem”. This thinking is underpinned by a critique of the deficit model that highlights that even though the gaps of knowledge have been identified several decades ago, it is still there, no campaign, no education has been able to shift or turn the tendencies (Brossard and Lewenstein, 2010).

Other views within STS state that publics have a more complex relationship with scientific knowledge than the deficit model assumes. Strong critique of the deficit model emerged in the nineties amongst STS scholars, who argue that just as the scientific community is not a homogeneous mass, the same is the case for the public, who is also made up of diverse groups with varied relationships to science and technological innovation. The equation is even more complex when examining controversial advancements such as biotechnology (Kerr, Cunningham-Burley and Amos, 1998). The weakness of the deficit theory mainly comes from the fact that it does not consider or “appreciate the contextual nature of knowing” (Sismondo, 2010, p. 175). Irwin and Wynne (1996) agree with other critics, also claiming that little to no attention is paid to other forms of knowledges that are relevant in everyday lives. Ziman (1991) claimed that the deficit model did not provide adequate analytical framework during their empirical studies and called for other factors to be added to the analysis.

Building on some of these critical insights, the *contextual model* vis-à-vis the deficit model posits that lay individuals “do not simply respond as empty containers of information, but rather process information according to social and psychological

schemas that have been shaped by their previous experiences, cultural context, and personal circumstances.” (Brossard and Lewenstein, 2010, p. 13). These unique contexts form reactions and shape perceptions of science and technology. Understanding in this sense is “not a binary condition... but rather a developing comprehension of both the meaning and implications of some knowledge, action or process based on appropriate commonly accepted principles” (Burns, Connor and Stocklmayer, 2003, p. 186). Opposed to the asymmetry emphasized by the deficit model, the contextual model not only implies symmetrical relationship, but also a public active in interpreting information. Instead of having a binary spectrum a wide attitudinal range was applied (Gregory and Lock, 2008). Understanding is a cocreation involving scientific and local knowledge (Gross, 1994). Miller (2001) also emphasizes the dialogue between the divergent actors within the contextual approach.

By isolating and targeting groups with diverging attitudes towards science and levels of science literacy science communication can be improved. Because of this it is important that the contextual model also acknowledges and emphasizes the role of media, representation and framing (Brossard and Lewenstein, 2010). The contextual model has mainly been applied to empirical research on risk perception and risk communication (Lewenstein and Brossard, 2006), placing significant emphasis on individualistic psychological issues.

Although different actors and stakeholders were incorporated into the contextual model, some STS scholars still find it faulty, with missing elements. Critics of the model i.e., Brian Wynne (1995, 2006) posit that the contextual model still emphasizes the problem points of the lay reactions while focusing on what divides scientists from layman. Although, the model seems less asymmetrical, it still highlights the interests of the scientific community and does not deal with issues of inclusion and participation (Lewenstein, 1992).

Partly in response to this critique, the *public engagement model* actively deals with and simultaneously engages the public with science. The model focuses on how it is possible to enhance citizen participation in creation of science policy, placing quite large emphasis on the fact that science must be democratized, and a sufficient dialogue should be created (Jasanoff, 2010). Scientific control can be taken from the elites – focusing on empowerment and political engagement (Brossard and Lewenstein, 2006; 2010). Llorente

et al. (2019) use the term ‘conversation model’ to refer to public communication of science that focus on the publics’ engagement.

The public engagement model aims to actively engage citizens, focusing on policy issues involving scientific and technical knowledge (Brossard and Lewenstein, 2010, p. 17). Public engagement is relevant because trust in science declined, the deficit of trust came into focus instead of deficit of knowledge. Instead of the emphasized frictions collective actions and participatory democracy became the focus (Gregory and Lock, 2008). Irwin (2006) sees engagement with science as a new opportunity for governance, while Collins and Evans (2002) questioned the legitimacy of scientific decisions that did not engage the public.

Critique of the public engagement model underscores that the model is very political and can be used to take stance in politics instead of providing a frame for a new type of public understanding of science. Barrier of the model that it often focuses on the process of science and not the actual content (Brossard and Lewenstein, 2006, p. 8). Alan Irwin and colleagues (2013) see the problem in the engagement model being too empirical, with less theory – the literature becoming just a compilation of engagement case studies or policy evaluations. Wynne (2006) posits that the minority opinions are still marginalized, and this can even lead to reinforce the power structures, by gaining public trust through the engagement for their already set approach and values and preventing alternative views from coming forth (Grove-White, 2001; Stilgoe, Lock and Wilsdon, 2014).

The last of the models, the *lay expertise model*, articulating “the importance of knowledge and expertise that is held and validated by social systems other than the modern science” (Brossard and Lewenstein, 2010, p. 15). This model is elaborated in the subsequent section, with greater detail since it serves as one of the theoretical backbones of the research project.

3.2.3.2. Lay expertise and lay experts

During the evolution of PUS models an alternative constructivist research approach was introduced (Kerr, Cunningham-Burley and Amos, 1998). According to Prior (2003, p. 43) this surrogate approach was formulated because medicine and other

scientific professional activities experienced a “legitimation crisis during the late 20th century”. This change in application can also be observed in the history of PUS methodology, when the way of inquiry shifted from large quantitative surveys to qualitative methods i.e., focus groups or deliberative methods. According to Martin Bauer (2008) this shift should also affect the terminology. As a result, he coins this type of inquiry Science-and-Society instead, because in his views, the label public understanding of science is linked to the deficit model.

Lay expertise is defined by Wilcox (2010) as follows:

“The concept of lay expertise has been used both narrowly, to refer to lay people’s active participation in the development of scientific and medical knowledge, and broadly, to refer to the general cultural stock of knowledge held by everyone in society.” (Wilcox, 2010, p. 45)

Lay experts thus by definition are “lay people possess some kind of special knowledge that neither trained experts in technology, ethics and social sciences nor professional politicians possess” (Myskja, 2007, p. 1). The term ‘lay expert’ originates in the nineties, Epstein (1995) in his work on AIDS patients sourced it to 1992 (Prior, 2003) but works discussing expertise of patients by contextual knowledge already surfaced in the eighties. Prior (2003) states the meaning of lay expert varied – some scholars claimed it was based on contextuality and had clear limitations, while others argued that lay knowledge could be on the same level as that of scientists. Others, like Barker and Garaldi (2011) or Nichols (2019) argue that lay expertise cannot and should not replace traditional, scientifically validated expertise. In agreement, the interactional component of lay expertise was emphasized.

Myskja (2007) distinguishes four separate meanings for ‘lay experts’:

- “(1) Lay people who are educated into quasi-experts on a particular issue or technology;*
- (2) Lay people who turn themselves into experts in order to challenge scientific experts;*
- (3) Lay people with particular knowledge based on tradition and experience;*
- (4) Lay people who represent an alternative perspective to expert views because they are non-experts”* (Myskja, 2007, p. 1).

Forerunner for these claims of the relevance of contextual lay knowledge is Brian Wynne, who conducted a series of empirical studies regarding several different scientific topics (most famous is most likely the investigation of how the Cumbrian sheep-farmers interpreted the Chernobyl catastrophe). Wynne (1991) claims that public understanding of science is a complexity of beliefs understandings and responses and also supposes supplementary knowledge from the laymen. Thus, understanding of science is linked to a unique situation in the views of Wynne, when there is personal motivation for the acquisition of the knowledge that takes a large effort from everyday participants. The lay expertise model in this sense “begins with local knowledge, sometimes called “lay knowledge” or “lay expertise” (Brossard and Lewenstein, 2010, p. 14). This concept of lay knowledge shall prove useful when analysing the patients’ experiences within the medical system, their relationships with doctors and other health care specialists.

This highlights one of the main tenets of the lay expertise model, that scientific knowledge is to some extent inherently tied “to the local circumstances of its production” (Sismondo, 2010, p. 175) While the deficit model aims to contrast lay knowledge to that of scientific professionals, the constructivist models states that it is possible for lay people to have opinions on complex social or ethical questions without it being a requirement for them to fully understand the scientific and technical processes that lay behind them (Kerr, Cunningham-Burley and Amos, 1998). The constructivist perspective has been used earlier to study the social perceptions and understanding of complex technology (Wynne, 2008).

To understand the lay expertise model, one must consider a definition of science that is different from what was used in the deficit model. In my research I will draw upon this unique definition of science itself, raised by Irwin and Wynne (1996). They state that science should not be understood simply as a ‘body of facts’, or a particular method, but instead seen as including a larger array of factors. They argue that science should be understood as a *‘diffuse collection of institutions, areas of specialized knowledge and theoretical interpretations’* (Irwin and Wynne, 1996, p. 7).

The boundaries of science are not set in stone, they are subject to modifications by other social institutions and forms of knowledge, thus the constructions of society are not merely embedded within, but also have the power to shape scientific constructs. Knowledge outside of the scientific tradition should not be ignored as in the deficit model,

and not unilaterally criticized for being irrational and misinformed (Irwin and Wynne, 1996; Sismondo, 2010). Misinformation and lay attraction to disinformation is a relevant threat to expertise and trust in the scientific community, but not all the public is influenced by false facts or direct manipulation (Bauer and Koltai, 2021; Krekó, 2021).

Throughout his seminal work Wynne claimed that the right way for studying the relationship of science and society is not through the exploration of the gap in knowledge between experts and lay society, but through examining the more complex mechanisms at work. Wynne in his research focused great efforts into constructing a theory he dubbed the ‘lay expertise’. Wynne claimed that in some situations the public may have a different, deeper understanding of scientific phenomena than the experts themselves. This highly criticized notion was in some respects misinterpreted as saying that lay expertise always surpasses expert knowledge, but Wynne (2008) claims to have cleared this misunderstanding of his theory. While proponents of the deficit model claim that scientist experts’ authority is omnipotent in these situations, in accordance with the constructivist tradition, Wynne claims that scientific authority is not a fixed disposition, knowledge systems are flexible and reflexive (both for scientist individuals, and scientific institutions (Wynne, 1995; Yearly, 2005). Lay experts in this sense are a type of watchdogs of science, guided by their mistrust of professionalized science practices. Lay expertise is partly accumulated through interactions with doctors or scientists (Arksey, 1994; Epstein 1996). Barker and Galardi (2011) argue that lay expertise is not neutral as it emerges from personal experience.

Drawing on works of Wynne (1991, 1992, 1996), Kerr, Cunningham-Burley and Amos (1998) during their study of lay knowledge on new genetics in society identified four distinct types of knowledge laypersons can possess about complex scientific issues. Kerr and her colleagues accept Wynne’s criticism of the deficit model and acknowledge the concept of lay expertise. Their empirical studies concluded that not only do laymen have these types of knowledges, but they are ready to mobilize them when interpreting science and technology related questions. These lay public held knowledge hubs are the following: *technical, methodological, institutional, and cultural* stocks of knowledge. Following Wynne, Atkinson or Lambert and Rose they also state that attitudes and “uptake of knowledge” is related to how relevant they perceive the innovation in their lives. As people are experts in their own lives, “expertise is therefore not solely the

province of professionals, but lay people have valuable knowledge and understanding of the social world which equips them to discuss the new genetics in a sophisticated and reflexive manner.” (Kerr, Cunningham-Burley and Amos, 1998, p. 52)

During the decades of PUS several interpretations of lay knowledge and lay expertise have emerged. While most scholars agree that Wynne’s work was groundbreaking, other strands of thinking also emerged in the STS field. According to Sismondo (2010) and Davies et al. (2009) while there are many problems with the traditional deficit model it is not wise to completely abandon it. Acknowledging that there is a knowledge gap, and that this can make the lay public susceptible to misinformation is crucial (Nichols, 2019) and lack of scientific knowledge also leads to negative attitudes towards scientific progress, technical advances, and the expert community (Rueger, Dolfmsa and Aalbers, 2021).

Critics argue that total abandonment of the asymmetry in the distribution between the groups can lead to false claims and feelings of expertise (Collins and Evans, 2002; Sismondo, 2010; Nichols, 2019). It has to be acknowledged that “genuine experts” on a topic have knowledge that non-experts simply lack, but this does not mean that the knowledge of the public should be neglected (see in detail the engagement model), but it should not be considered “lay expertise” (Collins and Evans, 2002). The author pair argues that the concept of “lay expert” is in itself an oxymoron and does not make sense to claim its validity.

Turning towards the relationship between the medical profession and ‘lay experts’, Lindsay Prior (2003), also, a critic of Wynne’s original interpretations, formulated hypotheses about the limits of lay expertise in the field of medical sociology and health and illness. Prior argued that in the medical field a boundary needs to be drawn around the domain of expertise and the concept of lay experts needs to be re-evaluated. He in fact argued (in agreement with Collins and Evans) that most of the time lay people are not experts. Experience-based knowledge is limited to an extremely small slice of reality, and the accumulated knowledge cannot be compared to official expertise and are prone to be erroneous.

Despite claims about the inaccuracy of the concept of lay expertise, works in the field of medical sociology agree that the last several decades have brought significant

changes to the doctor-patient relationship⁷ (Calnan and Williams, 1996; Freidson, 1970; Haug 1976; Tyreman, 2005). This is because laymen, patients do possess valuable insights and information (i.e., Epstein 1995, 1996). A shift towards the patient perspective (and emphasis on subjective experiences) changes the power hierarchy (asymmetry), focusing on an active instead of a passive patient and the style and content of communication – subjective patient accounts are (or should be) focused on (Calnan and Williams, 1996; Dupcsik, 2020; Pikó, 2006; Popay et al., 1998). Wilcox (2010) argues that when examining medical expertise, a middle ground should be adopted – in her paper, she puts forward that a great part of today’s knowledge is “collective knowledge that may be widely available yet is still unevenly distributed” (Wilcox, 2010. p. 45). Based on seminal works of Arksey (1994) and Epstein (1996), Wilcox states that the boundaries and interactions between professionals and expertise accumulating non-professionals should be the focus of study.

Similarly, Myskja (2007) positions himself between the two approaches – acknowledging the limitations of knowledge, but also arguing for acceptance of lay expertise as an independent source of knowledge. Thus, while Myskja (2007) accepts central ideas of Prior’s (2003) criticisms of the way ‘lay expertise’ was used in the works of sociology of health and illness but argues that should be room in theory and in practice for the ‘lay expert’ concepts. One such area is understanding of how lay people (especially patients) gather and accept knowledge. He argues that while ‘lay experts’ do in fact have a delimited area of expertise, parallel they are recognized by their peers as experts (some even in a wider part of society). He describes different types of lay experts such as the autodidact, the sage or the clear-sighted – their knowledges can be corrective of mainstream accepted views of science (Myskja, 2007, p. 6). Tyreman’s (2005) thinking reflects some elements similar to Kerr and colleagues, Myskja and Wilcox.

The underlying meaning of ‘expert patients’ presupposes that when making decisions about their own care, they will draw on their experiences and accumulated information (Rueger, Dolfma and Aalbers, 2021). Through connectivity patients “synthesize their collective illness experiences to produce interpretations and remedies

⁷ A detailed introduction of these changes are the core of the consequent theoretical chapter of the thesis.

for their conditions” (Barker and Galardi, 2011, p, 1353).

Henderson (2010) states that while medical decision making has indeed been democratized via lay expertise, it does in fact lead to diminishing trust in medical and scientific professionals. Accessing health related information and advice in internet communities the patients adopt a more decisive and prepared attitude, ready to challenge medical opinions, leading to frictions and open confrontation (Rueger, Dolfmsa and Aalbers, 2021; Smailhodzic et al., 2016).

Although Tyreman (2005) reduces this to a narrow segment in knowledge (echoing thinking of Irwin and Wynne), it should be taken into consideration during inquiry. The dependence on ‘lay expertism’, and how it can create a struggle of interest (Barker and Galardi, 2011; Conrad and Stults, 2010; Jasanoff, 2003) within the doctor-patient relationship will be introduced as relevant factor in both the subsequent theoretical chapters (highlighted for online health seeking behaviour patterns), both in the interpretational framework of the netnographic research portion of the thesis.

Discussion of reproductive technologies can be framed using all of the discussed models. In a topic such as illness or infertility the patients have significantly different type of expertise than do the doctors and this fact is often an important factor when viewing doctor-patient relationship (Bradby, 2009). The constructivist approach places emphases not only on the knowledge gap but focuses also on the public evaluation of the institutions they come in contact with (Yearly, 2005) (this being a very important element of my study of reproductive technologies).

3.3. Medical sociology

3.3.1. Changing doctor-patient relationship from the perspective of traditional medical sociology

The second theoretical framework that I incorporate into the thesis draws on the concepts and thoughts of medical sociology. From the extensive plethora of theoretical and empirical medical sociological knowledge, the subsequent parts mainly focus on the ideas and mechanisms underlying the changing relationship between doctor and patient, and patients' perception and trust of the medical profession and its institutions (Barker and Galardi, 2011; Hafferty and Castellani, 2019; Henderson, 2010). Understanding the forces and mechanisms influencing doctor-patient relationships is relevant because it has a potential to impact the provided care, or patient compliance. Patients' constructions of their illness and its understandings are impacted by these experiences (Cockerham, 2017).

Medical sociology deals with wide range of questions, it is one of the sociology's largest subfields (Barkan, 2017; Hafferty and Castellani, 2019). Cockerham and Scramler (2001, p. 3) posit that the aim of medical sociology is to apply theories and concepts from the sociological tradition to the topics of health and health care. Medical sociology thus places emphasis on issues of health, illness, health care services and organizations, public health, and health care policy. It encompasses research on inequalities in health status and access, medicalization, and the changes increasing consumerism brings forth in trust of medical services, staff, and organizations. A whole branch of medical sociological inquiry deals with treatments and influences on patient attitudes and issues of compliance (Barkan, 2017; Bradby, 2009). The field embraces a variety of quantitative and qualitative methodologies (Barkan, 2017), including online discussion analyses and netnography (e.g.: Elvey et al., 2018; Langer and Beckman, 2005; Pittman et al., 2017; Victoria Diniz et al., 2018).

Similarly, to what was described in the earlier chapters introducing STS, medical sociology is also considered a late bloomer within the realm of social scientific research (Cockerham and Scambler, 2010), even though health and illness has been the topic of investigation for centuries (the intellectual lineage originates in the late 1800s (Armstrong, 1998; Hafferty and Castellani, 2019). The past few decades have brought tremendous changes to medicine, health perception and medical technology, all impacting

its social imprint, and parallel changing the relationship between patients and medical professionals (Hellín, 2002; Hill et al., 2021). Since the widespread medicalization of health problems (Gore, 2013; Nichols, 2019) medical sociology and its theoretical perspectives have been influential (but not omnipotent) in guiding health related social scientific research. Applying frameworks inspired and guided by medical sociology to investigate infertility and medically assisted reproduction yet has too been less popular in Hungary than in western sociological community. Still the tenets of medical sociology have deep roots for other topics in the Hungarian sociological tradition (i.e. Buda, 1994; Dupcsik, 2020; Gaal, 2016; Molnár et al., 2017; Pikó, 2006; Rózsa, 2016; Szántó and Susánszky, 2006), so this chapter of the thesis will not attempt to give an overview of the field, it will be more concise and focused than the previous STS theoretical chapter, orienting the introduction to the relationship between doctor and patient.

Modern sociological approaches propose that there was significant change to the nature of doctor patient relationship, mainly with regards to the authority naturally associated formerly with the medical profession within the Western medical model (Gabe, Bury and Elston, 2013; Kaba and Sooriakumaran, 2007; Ritzer and Waltzak, 1988). By the end of the twentieth century the former passive role described by Parsons gave way to a more active and critical type of patient (Bradby, 2009; Pikó, 2006).

Synthesizing the relevant theoretical and empirical studies it emerges that the described major changes can be attributed to several factors: (1) the change in formation gap between doctor and patient, largely the consequence of open access to the medical knowledge in the digital area (Hardey, 1999; Cockerham, 2010); (2) increasingly consumer attitude of the patient in the institutionalized health care system (Davis, 2010; Vanderminden and Potter, 2010); (3) overall decrease in the trust towards professionals, especially in the medical field (Wynne, 2008); (4) rising level of lay activism and specific forms of lay knowledge (Davis, 2010; Epstein, 1993; Myskja, 2007). The following portion of the literature review will introduce and reflect on these changes and the underlying mechanisms. On the following pages of the dissertation, I will introduce how these changes are theorized and modelled in the selected literature taking on the doctor-patient relationship, drawing a line from the simpler traditional categorizations to models that showcase a wider range of influencing factors.

Turning first to the earlier relevant literature on the doctor-patient relationship:

one of first major theorists dealing with the interactions and interactional relations between doctors and their sick patients was Talcott Parsons (in Chapter 10 of *The Social System* (1951), titled “Social Structure and Dynamic Process: The Case of Modern Medical Practice”). Parson’s sick role incorporates basic guidelines for understanding mechanisms in the doctor-patient relationship. In his seminal work Parsons drew on core sociological theories such as role theory, deviance, and stigmatization. *“Health is included in the functional needs of the individual members of the society so that from the point of view of the functioning of the social system, too low a general level of health, too high an incidence of illness, is dysfunctional”* (Parsons, 1951, p. 430).

In accordance with his structural-functionalist model of society and the dominant systems view, Parsons introduced his concept of the sick role and the function of medicine in society. At the core of this interpretation is consensus and cooperation, alias a harmonious perspective of the dyadic relationship and interactions between medical professionals and their sick patients.

According to Gerhardt (1990) these elements are defined by the same value orientations, and the two roles are set against each other to achieve social control. Both willingly adhere to their roles (with a set of norms and assigned values), and the socially prescribed and unchallenged hierarchy between them. By doing so, deviance and conflict are avoided. Gerhardt (1989) distinguishes between the capacity model (core concept is the “failure to stay well”) and the deviancy/motivated model – in this latter the sick role is a mechanism of social control (Gabe, Bury and Elston, 2013). As we will see later in the chapter this over-accentuation of conformity was markedly criticized by later theorists, but the deep impact Parsons had on medical sociological thought was not questioned.

Parsons (1951) throughout his medical sociological path distinguished between two inherently demarcated roles of physician and patient. According to Milton’s (2017) and Barkan’s (2017) interpretations, Parsons argued that being ill was not only a biological condition, but rather adapting a new social role. The concepts of the sick and the professional roles rely on role theory, with its sociological and social psychological foundations dating to George Herbert Mead. Parsons’s conceptions were grounded in the interactions between doctor and patient and brought to light important aspects of social dynamic in the illness experience.

The basis of this differentiation is manifold. The two groups differ in attitudes, behaviour, social status, knowledge and the relationship are firmly hierarchical based on diverging obligations and privileges, roles and responsibilities. The terms sick and professional roles were coined and introduced, and their main attributes are summed up in the figure below.

THE PATIENT	THE DOCTOR
Rights <ul style="list-style-type: none"> Temporarily exempt from other roles – reduce activity Regarded as someone in need of care by society – cannot be blamed or punished for illness 	Rights <ul style="list-style-type: none"> Granted right to examine patients physically (and ask sensitive questions) Granted autonomy in professional practice Has authority in relation to the patient High status based on functional relevance and specific training
Obligations <ul style="list-style-type: none"> Seek out and submit to medical treatment as soon as possible Must want to get better Comply and cooperate with medical professionals 	Obligations <ul style="list-style-type: none"> Qualification and apply their skills and knowledge to highest degree Act for the welfare of the patient and not in own self-interest Demeanour is to be objective and emotionally detached Oblige to specific rules of professional conduct

3. Figure: Social roles of doctors and patients (obligations and privileges based on a synthesis of Parson's theoretical work (1951) and its interpretations of Milton (2017).

Illness in the Parsonian framework is interpreted as a form of social deviance affecting the rippleless functioning of society, which disruption is to be corrected as soon as possible. If too many claims to be ill, it would have a dysfunctional impact on society – thus the obligations of the sick role. In his harmonious functionalist view both groups will adhere to their assigned roles to make the transition back to routine as seamless and rapid as possible, to maintain the well-being of society. This requires a (by today's standards) simplified sick role, with uniform illness behaviour (Hafferty and Castellani, 2019; Milton, 2017). Parson's model is highly paternalistic, the patient seeks help from doctors, and then comply fully with the diagnosis and treatment decisions of the

physician. The interaction between the two roles is both asymmetrical and imbalanced. Parson's roles are based on his thinking of the ideal doctor-patient relationship, drawing on thinking of Freud, the relationship is built up like the parent-child association. The patient is a passive and subordinate role, complying to the active actor in the alliance the doctor. As we can see in the figure above these roles come with a set inventory of obligations and rights towards each other.

The rights and obligations of the sick role are the following (based on Parsons 1951, and its interpretations by Milton (2017)). Rights of the ill: (1) temporarily exempt from performing other roles (such as occupational roles or familial obligations) for the duration of the illness; (2) the sick cannot be blamed or punished for their illness – their condition must be accepted by society and their care arranged. Parallel to these rights the sick role assigns obligations as well: (1) the sick has an obligation to seek out treatment to get better as soon as possible, and (2) must comply and cooperate with the professional help received. At the other end of the relationship is the professional, the doctor. Their rights in the Parsonian framework are as follows: (1) high status based on their functional relevance, and long specific training; (2) autonomy in professional practice especially health decision making; (3) authority in the relationship with patient – it is their prerogative to assign them the sick role and suitable treatments; and (4) right to examine patients, and access intimate details about their conditions and health behaviour. In par with their specific rights medical professionals' role also includes several obligations: (1) must be qualified and trained and use their knowledge to its full capabilities; (2) professional gains must take a backseat to concern and care for the patient and community; (3) their demeanour must be objective, and they have to stay emotionally detached from the sick; and (4) they must oblige to the specific rules of professional conduct.

While it is undeniable that Parson's work was ground-breaking and laid the path for decades of medical sociology, the Parsonian frame was critiqued from several aspects, especially since the boom of medical advancement in the past half century (Monaghan, 2013). The harmonious view of the relationship was questioned by later theorists, belonging to traditions of conflict theory as well as symbolic interactionism (Ritzer, 2008). As such Glaser and Strauss alongside Goffman (Glaser and Strauss, 1965; Goffman, 1961, 1967) all placed emphasis on the individuality and diverging nature of

relationships between patients and medical professionals. Conflict theories on the other hand focused on the classes of the interests of the above-mentioned groups (Cockerham and Scambler, 2010; Freidson, 1970). Primer objections focus on the asymmetry and the emotional detachment from the doctors' perspective, while also neglecting the patient behaviour and conditions of chronic illness (Burnham, 2013; Freidson, 1970). These challenges of the Parsonian concepts lead to later developed models introduced on the following pages.

Mitigating aspects of long-term illnesses were introduced later (Parsons, 1970). Basing the model on a purely ideal version of the doctor-patient relationship was argued against by both conflict theorist and constructivists, scholars of both traditions saw it as unrealistic and unable to hold up in real-life social interactions and relations (Byrne and Long, 1976; Freidson, 1970; Turner, 1992). Critiques also touched upon how the relationship has changed in time and space – lead by macro level changes, giving way to micro level individual preferences grounded in expanding consumerism and access to knowledge – which was in Parsons's model the property of medical professionals (Haug, 1976; Willis, 2015).

Hellín (2002) states the problems within this framework, as the parent-infant relationship is mirrored: the patient is like an infant or a child, wholly dependent on the parent (doctor) for all information and decision-making. “Good patients” are submissive – they obey the proper orders and act in prescribed manner, while bad ones question the authority or even knowledge of the medical professional. Critics argue that this might be detrimental to compliance and thus healing – Balint (1964) proposed that the doctor-patient relationship should actually be interpreted as what he called “mutual investment”. For Hellín (2002, p. 451): “the function of the physician is not to expropriate the patient's illness. On the contrary, their function is to help them appropriate it.”

Mead and Bower (2000) also advocated for shared power and responsibility between doctor and patient. This type of approach and terminology reflects one of the mechanisms behind the evolution of the relationship, namely the rise of consumerism and its effect on patient expectations (Haug, 1976). At the same time moral agency must be awarded to patients (this will be discussed in detail, in a subsequent part of the thesis dealing with delegated biopolitics and informed consent). Scambler, Scambler and Craig, (1981) point out that the model cites medical professionals as the sole source of medical

information for the sick. In their study the authors underline the importance of family and friends, and as we could see in previous chapters contextual knowledge and the rising role of the internet in health information seeking increasingly underlines this line of critique.

As it has been shown, the aforementioned asymmetry, resulting in the almost total lack of active patient participation are at the core of critiques of the Parsonian model (e.g., Gaal, 2016; Rózsa, 2016). Opponents emphasize the emergence of “a more active, autonomous and thus patient-centred role for the patient who advocates greater patient control, reduced physician dominance and more mutual participation” (Kaba and Sooriakumaran, 2007, p. 57). By today, a patient-centred approach has become predominant in medical practice (Cockerham, 2021; Miller, 2017; Rózsa, 2016). This of course implies a different understanding of the patient (than the sick role), focusing both on the medical symptoms and at the same time their humanity, emphasizing the “importance of an intimate relationship between patient and physician (...) because in most cases an accurate diagnosis, as well as an effective treatment relies directly on the quality of this relationship” (Hellín, 2002, p. 450).

The interactional relationship between doctor and patient does not necessarily have to be grounded in asymmetry as theorized by Szasz and Hollander (1956). In their early influential work advocating greater patient involvement in the field of psychiatry, the authors formulated three models of the doctor-patient relationship also applicable to other medical environments: (1) active-passivity; (b) guidance co-operation; and (3) mutual participation. The first two of these are more in line with the thinking of Parsons (being paternalistic and predominantly doctor-centred), while the latter reflects those of Hellín (2002), Mead and Bower (2000), Haug (1976) with their patient-oriented focus.

Model	Physician's Role	Patient's Role	Clinical Applications of the Model	Prototype of the Model
Activity – passivity	Does something to patient	Recipient (unable to respond or inert)	Anaesthesia, acute trauma, coma, delirium, etc.	Parent-infant
Guidance – cooperation	Tells patient what to do	Co-operator (obeys)	Acute infectious processes, etc.	Parent-child (adolescent)
Mutual participation	Helps patient to help himself	Participant in „partnership” (uses expert help)	Most chronic illnesses, psycho-analysis, etc.	Adult-adult

4. Figure: The three basic models of the physician-patient relationship based on Szász and Hollander (1956, p. 586)

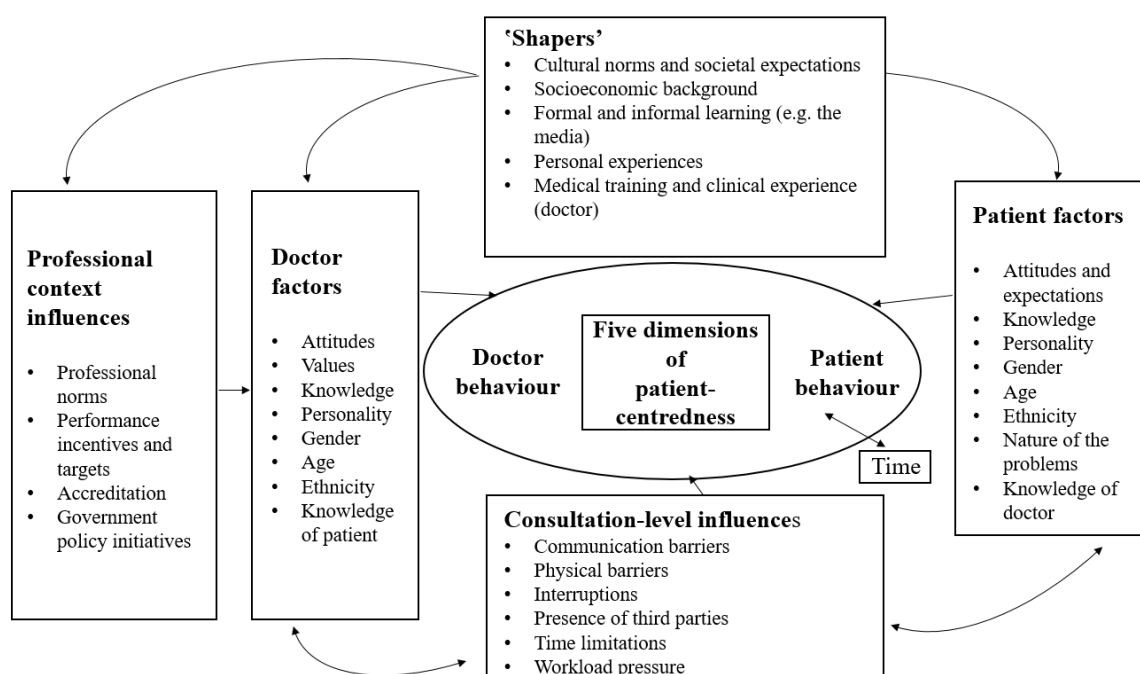
The mutual participation model is favoured by those patients, who “want to take care of themselves” (Szasz and Hollander, 1956, p. 587), or at least feel the need to be adequately informed, to partake responsibly in certain decisions regarding their treatments. The nature of the relationship is mutually interdependent, with limited asymmetry in power. This latter notion of assuming almost equal power relations has been criticized along with the traditional medical model by theorists following the Foucauldian tradition of biopolitics and biopower (e.g., Lazzarato, 2006; Rabinow and Rose, 2006).

A model created by Hayes-Bautista (1976) focuses on how patients aim to discuss and modify treatment with their physicians. This type of patient interaction is the direct opposite of the passive, subservient sick role described by Parsons, and even goes beyond the mutual participation model of Szasz and Hollander. This interaction is embedded in conflict and emphasizing expertise and power. The process is depicted as a form of negotiation – patients question their doctors and seek validation from other sources – like family, or more recently the internet (Barker and Galardi 2011; Cockerham, 2017, Gaal, 2016; Molnár et al. 2017).

Bury (1997) in his work synthesizes the Parsonian (1951) and the Szasz-Hollander (1956) models with the interpretations of Hayes-Bautista (1976). Early criticisms were foremost arriving from Freidson (1970), who argued that activity and passivity should not be set, and it is possible for the doctor to be passive and the patient active. (This line of thought is echoed in earlier introduced PUS models, namely the lay expertise and the engagement models.). Bury proposed a triad in his modelling: (1) consensus model – with

close association to Parsons's paradigm; (2) conflict model borrowing its foundation from Freidson (1970) and emphasizing that doctors and patients "live in different social worlds" (Bury 1997:86) with diverging spheres of knowledge; (3) the negotiating model supposes that both patient and doctors are active, and the consultation is a shared event. Later, taking into consideration the changes and trends of society and economy, this triad was augmented by a fourth element, (4) the contractual model, which was more in line with the consumerist attitude and position adopted by patients by the end of the century. The consultation, and the discourse taking place between the actors of the dyad should be more equalized, taking into consideration the patients' accounts, knowledges and accumulated expertise (Tuckett et al., 1985).

To rectify the simplification of previous models, Mead and Bower (2000) developed a complex patient-centred model better suited for the increasingly complex context of the 21st century, to show the diverse influencers of the doctor patient relationship. The benefit of their framework that it takes into consideration the changes that have occurred in the last few decades as well as a myriad of factors that make their model less abstract and more applicable to interpreting the changing relationship from the patients' perspective.



5. Figure: The patient-centred model based on Mead and Bower (2000, p. 1104)

As the processes and relationships vary cross culturally and socially, they must be taken into consideration (Williams and Bendelow, 1996). The importance of macro- and micro contexts makes the model unique and an evolution from the earlier introduced Parsonian or Szasz-Hollander models. Adding of cultural and personal contexts or “shapers” makes the model more applicable for 21st century medical sociological inquiry.

3.3.2. Changing doctor-patient relationship from the perspective of biopolitics and biopower

Changes in the doctor-patient relationship should not only be viewed from the traditional aspects of medical sociology as seen above but can be framed through the existing power relations in the realm of medicine and the healthcare system. Below I introduce influential concepts that can be fruitful in answering my research questions which investigate the interactions within the doctor-patient relationship.

It is important to note that my thesis is not grounded in the Foucauldian tradition of investigating health care, so it is not dedicated fully to investigating biopower and mechanisms of biocontrol. That would be an undertaking of an entirely different manner, and complexity – the framework for an entirely different thesis project. With this in the dissertation I merely aim to contemplate one angle, on narrow aspect of the biopower tradition from many, that may help understand the factors influencing women’s treatment decisions and experiences, focusing on the perceptions they share about their relationship with medical professionals throughout their infertility treatment journey.

3.3.2.1. From delegated biopolitics to professional biopolitics

The concept of delegated biopolitics and professional biopolitics dubbed by Memmi (2003) is linked and contrasted to the traditional, early Foucauldian (1975) notion of biopolitics. In the original concept the states have power and control over the bodies of individuals. Memmi, on the other hand states that this dichotomy is not always the case, and the state has relinquished some regulatory control over to the medical professionals and their lay patients. During the seventies and eighties decisions were delegated to the patients, the height of their autonomy. Later their bodies became controlled again through the physicians professional biopower, and in this sense there was a sort of dual constraint (Memmi, 2015).

In this sense the omnipotence of state power is controlled by the power of the doctors, who have the everyday contact with the patients themselves and through discursive acts, their framings and recommendations lead the patients. This act starts with what Memmi sees as: “one must present oneself before a physician” (Memmi, 2003, p. 648). Part of this power, despite the professionals’ control is further delegated onto the patients in the form of treatment decision-making.

In this framework the regulation takes form not through disciplining of bodies (regulation and punishment), but rather a new type of surveillance through different forms of discourse and speech of the medical professionals (“removal of the penalty” as coined by Memmi, 2003, p. 645). But as Memmi (2015) states, this is merely a perceived form of liberation of the citizen (even though the subjects are much more independent and self-reliant when making health-related decisions).

In the interpretations of Memmi both the doctors and the patients are the subjects of delegated biopolitics, and the power exerted in discourse has moved to communication between doctor and patient, which is a natural part of the doctor-patient relationship. In this sense the discursive style and the chosen medical information shared by the doctors, influences, and thus controls the decisions and acts of their patients. Patients may or may not be fully equipped to understand, digest, and utilize these medical facts in their decision-making practices (Memmi’s interpretation of the capacity of patients to make complex and controversial decisions differs from the earlier introduced opinion of Kerr, Cunningham-Burley and Amos (1998)).

Another factor to consider when introducing delegated and professional biopolitics, that decision-making in this medical framework requires a certain behaviour or “habitus” not only from the medical professionals, but it also supposes informed, rational and calculated behaviour from the patients as well (Memmi, 2015). Yet as Memmi (2012), Fannin (2013) and other scholars point out, in the case of difficult procedures or controversial technologies, this type of rational behaviour and decision-making is often lacking from the patient’s side, positioning them in stressful situations. As Memmi posits that this type of decision-making delegation places a significant and previously unexperienced burden on the individual choices of women. Reproductive decision-making still has a gendered nature, bestowing extra genetic responsibility on women (Reed, 2012). Empirical research has shown that some reproductive decisions are

so complex, the agents themselves are not prepared to handle them. Fannin refers to these effects of delegated biopolitics of reproduction as “the burden of choosing wisely” (Fannin, 2013, p. 281).

Drawing on the concepts of Memmi, Fannin during the investigation of French maternal healthcare, located new sources of power that occur through discourse, that she refers to as “government through speech” (Memmi, 2003; Fannin, 2013). Fannin expands on the recognition that women now opt to take a more active role through the course of their pregnancies and their births than before and argues that this involvement can possibly give greater autonomy for the women involved. Delegated biopolitics through achieved patient agency, also has an effect on the doctor-patient relationship. The patients or the users of the given technology will be more active and involved, and the professionals are made to take their opinions and positions into consideration as well. According to the delegated biopolitics framework this change in influence is directly linked to the way patients are informed about their health and treatment conditions, which in turn influences the decision-making process. As in the previous introduction of doctor-patient interactional models we could see that the asymmetric relationship has evolved, from a rigidly hierarchical one, to a more horizontal connection, with more equalized rights and obligations. An important aspect of this change in the doctor-patient relationship is the concept of informed consent. In the subsequent portion I will elaborate the concept of informed consent, which is underlined by the medical ethical principle of autonomy (Selinger, 2009).

3.3.2.2. *Informed consent*

As introduced above, delegated biopolitics places emphasis on the communication between the medical experts and the patients. During these communicative acts the concept of informed consent becomes extremely relevant, as it is the core of patient decision-making. *“The principle of informed consent requires that health professionals, before any diagnostic or therapeutic procedures carried out which may have any reasonable possibility of harm to the patient, explained to the patient what is involved in order to secure the understanding consent of the patient to proceed”* (Kirby, 1983, p. 69).

Before and during the treatment process, the patients must be adequately instructed about all the possible risks and benefits of the suggested procedures, as well as

its alternatives, including the prospect of bypassing medical treatment altogether (Herbert, 1980 in Kirby, 1983). The patients then evaluate all the given information before making their decisions. Selinger (2009) posits that there is a difference between consent and informed consent, and this is the knowledge and understanding of the patient behind the consensus decision (Málovics, Vajda and Kuba, 2009).

As seen in the previous sections, the traditional concepts of the doctor-patient relationship have changed in the last decades, and the personal preferences and attitudes of the patients have also become a significant part of medical treatment processes (Kovács, 1997). According to Memmi (2012) this change is reflected within the discourse between doctors and patients, where the voice of the patients is more influential than previously. Informed consent is the concept that mainly allows this change to occur, making the traditional hierarchy between professionals and laymen less significant (Kovács, 2004). The concept of consent is quite new in the doctor-patient relationship, only coming into focus the decade after the Nuremberg Code (Habiba, 2000), and somewhat levelling the previous asymmetry of the doctor-patient dyad, and its interactions.

According to Kottow “*the basic tenet of medical ethics is that people whose body is to be interfered with, be it for therapeutic and/or research purposes, ought to be fully informed about the intended procedure prior to expressing their uncoerced, explicit, and revocable acceptance to participate*” (Kottow, 2004, p. 565). One of the foundations of informed consent is that the patient is “*entitled to information which is sufficient to provide him with the opportunity to make a rational decision*” (Sen, 1995, p. 197). Thus, information and its proper communication are at the core of patients’ medical consent, as “*permission granted in the knowledge of the possible consequences*” (Habiba, 2000, p. 183).

Moreover, informed consent makes it an imperative, that medical assistance and treatment can only be applicable on patients after they have been “properly informed” and have consented to the procedures suggested by their clinicians (Sándor, 2005). This is a highly perplexing ethical dilemma, since informed consent presupposes that the patients possess an understanding of the complexities relating to their medical conditions and can adequately weigh their options before making their decisions. This difficulty is highlighted by findings about lay morality, spare embryos and embryo vitrification

published by the author of this thesis and her colleagues (Sándor, Vicsek and Bauer, 2017, Vicsek, Bauer and Szolnoki, 2019; Vicsek, Sándor and Bauer, 2021).

Whilst informed consent overall has an equalizing effect on the hierarchical doctor-patient dyad, but scholars like Memmi (2012), Kottow (2004) and Fannin (2013) point out that significant inequalities in the relationship persist, as the medical professionals keep discursive authority to influence patients through professional biopolitics and pressuring through emphasizing their own opinions.

Kottow (2004) as such argues that the desired informed consent often remains an abstract concept, a wished goal in the doctor-patient relationship, as clinical circumstances make it often difficult to fully respect patients' autonomy. Thus, in practice the full autonomic nature of patients regarding their decisions is a desired illusion (Maier-Shibles, 2011 quoted by Memmi).

Moreover, factors such as cultural and educational differences come into play as well and according to Macklin (2001) a difference between “aspirational ethics” and “pragmatic ethics” can be observed. Dodds (2000) argues that in clinical practice the full autonomy ideally insured by informed consent does not occur and is replaced by relational autonomy. Critics of informed consent declare that there are often structural and knowledge problems in giving full autonomy to the patients (Kottow, 2004).

3.3.3. Summarizing the interactional changes in the actors of the doctor-patient dyad

Development in the models have shown significant changes in the main actors of the interactional dyad (introduced above). Light and Levin (1988) see a paradox in the medical advancements and parallel professional decline. Doctors have suffered significant power-loss – their expertise constantly being challenged by increased consumerist demands and lay involvement (Cavenagh et al., 2013; Nichols, 2019). Doctors were no longer perceived to be flawless and altruistic – doctors are not only seen as working selflessly for the good of the patients, and as consumerism swept in patients became more demanding clients (Cavenagh et al., 2013; Cockerham, 2017, Johnson and May, 2015; Nichols, 2019; Theorell, 2000). The perception of the ideal doctor changed from caregiver, to overregulated professional (Boyer and Lutfey, 2010; Cavenagh et al., 2013, Málovics, Vajda and Kuba, 2009), and educated lay expert patients' medical

sociology and science communication have (or should have) placed emphasis on the importance of a new type of professional communication (Cockerham, 2021; Dupcsik, 2020; Molnár et al., 2018).

Patients socialized in consumerist society and with more available information expect the encounter with the professional to be seamless (Málovics, Vajda and Kuba, 2009; Potter and McKinlay, 2005; Rózsa, 2016). Their subordinate position has changed, the authority connected to the doctors' role has less significance (Cockerham, 2017, 2021; Gabe, Bury and Elston, 2013; Haug, 1976). Parallel they adopt a more active role and have gained significant agency and independence via access to medical knowledge, and parallel have grown to be critical and reflective towards professionals, and authoritative institutions in general (Sulik and Eich-Kroh, 2008). From the perspective of knowledge, the Internet plays a significant role in this elevated agency (Bauer and Koltai, 2021; Gaal, 2016; Nettleton et al., 2005; Nichols, 2019). The e-patient aims to have as great a role in their treatment as possible, from knowledge gathering, to suggestions and negotiations with the medical professionals (participatory medicine) – for this they use Internet search tools and information collected from social media. This acquired knowledge – in cases lay expertise brings them independence and emancipation from the traditional passive sick role (Eysenbach, 2008; Molnár et al., 2018). The knowledge and the lay expertise of patients is introduced from the approach of science and technology studies in earlier Chapter 3.2.3. 2.. On the other hand, many less “professionalized patients” (Stöckl, 2013) sometimes still struggle with the decisions pushed onto them, especially when complex or morally perplexing determinations need to be made (Memmi, 2003)⁸.

⁸ For greater detail about informed decisions and delegated biopolitics see earlier dissertation chapter.

3.4. Gender roles and the prenatal

In the last decades significant changes have occurred in the roles women and men assume during pregnancy and child rearing. A large myriad of both theoretical and empirical literature is available, investigating how the realm of domestic life has undergone significant transformation – this including re-gendering of housework, childcare and the prenatal (e.g., Annandale and Clark, 1996; Ettore, 2002; Lindsey, 2017; Rapp, 2000). Moreover, due to the advances in the technology of assisted reproduction: “the strictly biological definitions of parental roles are abandoned” (Fuscaldo and Savulescu, 2005, p. 166).

This chapter of the dissertation explores the prenatal, infertility and partaking in medically assisted reproduction through the lens of gender roles, relying on theoretical and empirical foundations of gender role theory. On the subsequent pages I will introduce the main points of gender role theory in relation to social expectations for biologically related children, fertility, and reproduction as well as new reproductive technologies.

As these gendered aspects are part of a holistic approach in the thesis, I will not attempt to look at a broad range of theories within the realm of gender studies. Neither is it my goal or place to make normative claims about issues related to gender. As it is an entire sub-field researched by many, I will not look at the implications of gender as a non-binary concept, and moreover I will steer away from investigating identity politics. While these fields of sociological interest are burgeoning and valuable – and my lack of focus is not stemming from neglect, they are not the approaches that can facilitate in answering my research questions. Thus, instead I will aim to focus on an objective description and interpretation of how gender roles and reproductive technologies are interconnected, and how assuming certain gender roles influence behaviour during medically assisted reproduction. This chapter will aim to explore phenomena of the gendered nature of reproduction – and enumerate and analyse the dissimilar roles that are ascribed to women and men, focusing on its changes and cultural contexts. The theoretical chapter will again lay the groundwork for angles of the thesis’s empirical investigation.

Following early works of Eagly (1987, p. 6) the term gender and gendered are used to underpin meanings and interpretations “*societies and individuals ascribe to female and male categories (...) social roles a society defines for women and men as*

gender roles and the stereotypes that people hold about women and men as gender stereotypes.”

Roles and role theory also played an important part in earlier chapters introducing the Parsonian concepts of the sick and doctor roles, and their interactional relationships. Subsequently, a role is defined as “*the expected behaviour associated with status*” and such roles are “*performed according to social norms, shared rules that guide behaviour in specific situations*” (Lindsey, 2017, pp. 2-3) and regulate individuals’ social behaviour (Eagly, 1987). Gender role theory is based on the premise that males and females are ascribed and occupy different private and public roles within existing social structure, and that social behaviour is assessed and regulated based on the social roles connected to these sex differences (Eagly, 1987; Littlejohn and Foss, 2009).

Eagly posits that we must view “social roles as determinants of sex differences” (Eagly, 1987, p. 8). This social role theory of gender turns away from purely biological theories (Fausto-Sterling, 1985) and emphasizes the societal and historically transforming component of gender differences. Richardson (2015) argues that gender is culturally determined, and people are gendered through socialization into their gender roles. In reproductive and family relations, traditionally women were categorized as mothers, while men had breadwinner roles. Recent studies have painted a more complex form of gender organization and role entanglement. Similarly, roles do not have the same contextual meanings for men and women (Lindsey, 2017).

The theoretical perspectives of gender roles are manifold, the dissertation draws upon interpretations emphasizing micro levels of analysis, although it does acknowledge that gender roles assumed during medically assisted reproduction and the prenatal are highly influenced by mechanisms of the macro and mezzo levels. This interactionalist perspective allows for the actors to adhere to cultural norms yet supposes the latitude to be able to modify roles in social interactions and bring their own concepts of appropriate behaviour (Lindsey, 2017).

Although recent strain of literature focuses less on roles and more on femininities and masculinities, gender role differences are not abstract concepts from the academic realm, they can clearly be observed throughout the path of maturation and family formation, making it a salient theoretical sub-frame for my dissertation. On the next pages

I will look at how pronatalist views influence gendered expectations on childbirth and childlessness. Then I will turn my attention towards the gendered behavioural expectations during medically assisted reproduction and the prenatal.

3.4.1. Pronatalism – gendered expectations, unequal burdens

Most societies regard childbearing as an inherent part of life and maturation, and as many authors have pointed out, the societal pressures for women are much greater (Bartels, 2004; Greil, Leitko and Porter, 1988; Mills, 2011). As Western societies experience decline in fertility rates, and more and more women and men decide to live a childfree life-course, population politics and policies are set out to promote family formation and raising biological children. Pronatalist governmental thinking and policies are set to advocate and forward this agenda.

At the core of pronatalism is the encouragement of all births. According to Heitlinger (1991, pp. 344-345), several levels of pronatalist encouragement of childbearing can be identified: (1) cultural dimension – motherhood is conceptualized as natural and central to the identity of women; (2) ideological dimension – motherhood is a patriotic, ethnic mandate / obligation; (3) psychological dimension – identified with micro level aspirations and emotional decision-making; (4) macro, cohort dimension – birth rate is related to earlier generations; and (5) dimension of population policy and state interventions to influence and regulate the dynamics of fertility. While all these dimensions, and micro-macro level influences may affect the birth-rate positively, they also most certainly place significant burden on their main targets, the women (Parry, 2005; Rivkin-Fish, 2010). Heitlinger (1991) argues that loud and coercive pronatalism can severely limit reproductive freedom, especially when the birth-rate growth is reached through limited access to legal abortions (one must look no further than recent Polish legislation). Kerr (2004) notes that these selective laws all have major impacts on choice – even if the coercive nature “only” takes on the form of social pressures (Rapp, 2000).

Numerous manifestations of pronatalism today can be called selective – urging and supporting some desired segments of the population to have (more) children, whilst deviating others – i.e., singles, homosexuals, or older women – from family formation (Rivkin-Fish, 2010). As such, these pronatalist practices usually have the consequence of reinforcing the traditional family models, with their linked gender roles. The cultural and

ideological levels intertwined with the social policy dimension through targeted support, the traditional breadwinner father and the homemaker mother roles are strengthened (Heitlinger, 1991; Sági and Lentner, 2018; Szikra, 2018; Szalma and Takács, 2012).

Blood relations and genetically related offspring are the most valued in pronatalist societies and attitude towards childlessness is diverse. Voluntary childlessness (or the childfree lifestyle) is shunned and punished through social and family policies (for detail see chapter 4 of the dissertation) (Szalma, 2021b). Involuntary childlessness has a more fragmented judgement – i.e., in Hungary the government places high emphasis on supporting infertile couples seeking medically assisted reproductive solutions (first five, then from 2020 six IVF cycles are financed – making it one of the most generous financial support), but continuously limits access, narrows the group of citizens who can participate in these treatments, and also aims to nationalize institutions, private fertility clinics. These limitations are in line with the traditional family model propagated by the Hungarian government. Specific Hungarian pronatalist social and policy measures will be introduced in greater detail in fourth chapter of the thesis.

These pronatalist attitudes place a heavier burden on women than men, strengthening the less modern gender roles – placing most of the reproductive and genetic responsibility on women (Heitlinger, 1991; Parry, 2005; Rapp 1994, 2000; Rivkin-Fish, 2010). As mentioned above attitudes towards involuntary childlessness ranges from absolute stigmatization (e.g., Pakistan, Iran), to seemingly relative acceptance. But in discourse and semantics infertility or “barrenness” is still blaming women despite the medical evidence showing that men and women can equally have fertility problems. Pronatalism in this sense assists in linking a women’s value and self-worth to the ability to conceive and bare children both on a macro and a micro level (Arghavanian et al., 2020; Heitlinger, 1991; Parry, 2005; Rivkin-Fish, 2010). This can strengthen gendered behavioural patterns linked to pregnancy and childbirth (Reed, 2012) as discussed on the following pages of the dissertation.

3.4.2. Pregnancy and childbirth – gendered expectations, gendered behavioural patterns

According to Reed (2011, 2012), most of the literature on reproduction with a gender focus relates to women. Locock and Alexander (2006) even argue that men’s roles,

status, and feelings are often overlooked in studies, and should be a focus of further research. While I agree with this quest, unfortunately as detailed in the methodology section of the dissertation my investigation also looks at the female perspectives.

This gap in representation has a dual explanation: firstly, a great mass of reproductive and procreation related social scientific research is grounded in one of many feminist traditions, while secondly, we can identify a much more down to earth explanation, namely that men are a much harder to reach research population in health investigations and especially reproduction related queries (Hirsch, 1999).

Rapp (2000) notes that based on existing findings, there is a duality as both the obligations and the rights of reproduction are gendered, and thus are placing reproductive responsibility unequally on women. As illustrated above, the obligation for family formation, and the stigmatization burden for childlessness is harsher on women.

Parallel to these gendered obligations, gendered rights also appear. Historically in most of the literature, women as mothers are identified as the “primary parent”, while the role of fathers is often described as secondary and passive (Ettore, 2002; Rapp 1994).

Belonging to the earlier feminist strand of thought that women are more connected and thus have more rights to the baby, Sandelowski (1994) argues women and men have different relationships to pregnancy and the foetus. One reason stated is that for women pregnancy is a continuous experience, while for men it is discontinuous – “the genetic inseminator role is separated in time and space from the nurture role” (Sandelowski, 1994, pp. 233-234). In this connotation women are the “exclusive guardians of the foetus” (Rapp, 2000). The last few decades have shown a shift in family dynamics and some equalization. Traditional parenthood roles and behaviours have adjusted, the former passive father role has evolved into a more active, contributing one – the emergence of “new fatherhood” (Dick, 2011; LaRossa, 1997).

The focus on purely biological fatherhood now has been replaced by a group of social roles during pregnancy and childbirth (Dick, 2011; LaRossa, 1997). Naturally, this type of shift in parenting is not a global or even an all-encompassing change – many mothers are still taking on most of the responsibilities (Birenbaum-Carmeli, 2003; Birenbaum-Carmeli and Inhorn, 2009; Lindsey, 2017). Just as men are transforming with new father roles, women are also adopting new roles, especially in emerging traditional

social contexts, where motherhood is augmented with other types of decision-making (Arghavanian et al., 2020). Richardson (2015, p. 166) articulated the mechanisms quite concisely: *“The complexity of men’s roles highlighted in the prenatal arena is indicative of diverse and fluid nature of masculinity articulated within contemporary Western society”*.

In a series of studies, Reed (2009, 2011, 2012) investigated if gender does in fact effect genetic responsibility, and how do these behaviours compare to traditional gender roles, and gendered decision-making reasoning. She looked at gender dynamics in relation to multiple types of reproductive technologies and concludes that there are a “paradoxical set of gender roles” (Reed, 2012, p. 93). Working with inductive reasoning and modified grounded theory, her results transcend mere empirical insights and significantly adds to the knowledge on gender roles and reproductive technologies, serving as a solid inspiration for my own research.

Firstly, there is evidence for solidifying traditional gender roles and division of labour in reproduction and genetic responsibility. Namely, women establish their roles as *guardians through gate-keeping information*. Women are often more active in health seeking behaviour when it comes to reproductive or genetic technologies from traditional formal medical sources (Markens, Browner and Preloran, 2003; Reed, 2003). According to Reed (2012) this gendered relation to information seeking and disseminating reinforces traditional gender roles (and creates “genetic exclusivity”) on two levels: (1) within the pregnancy partnership; (2) through dissemination, women are sharing information – many interacting health professionals (nurses, midwives) are women.

Information seeking on the internet is gendered in a more complex manner – and can both reinforce or break down traditional gender roles. Whilst men often search for information, but the research shows that it is often at the behest of their partners (Reed, 2012). In addition, when examining the information spread in online discussion groups it is acknowledged that women are much more likely to gather information there (Bauer 2014; Lowe et al., 2009). Still the internet plays an important part in increasing men’s participation and taking on the new type of father role early on, with many to be fathers focusing on technical and medical information, but much less on support group communication (Jackson et al., 2001). Locock and Alexander (2006) even coined this mode of participation “gatherer and guardian of fact”, which shows a notable change to

traditional gendered parent roles.

Secondly, there is evidence that through medical and genetic decisions, the walls of traditional parenthood gender roles are crumbling down (Reed, 2011, 2012). *Reproductive and prenatal decision making* in the traditional view was mostly the prerogative or burden of women. Recent studies have highlighted that in their new fatherhood role, men have become increasingly active and involved in mutual decision-making and enforcing, or supporting (Dick, 2011, LaRossa, 1997, Locock and Alexander 2006). Involvement is viewed on a spectrum: (1) at one end controlling male participation (need for their “approval”), that solidifies traditional roles, (2) whilst at the other end, full supportive joint decision-making that encourages the new types of gendered genetic responsibility (Markens, Browner and Preloran, 2003).

Reed (2012) argues that at times it is the female partner who wants to keep the control and adhere to the traditional maternal gender role, while the men want a more active role in genetic decision-making (Reed’s findings suggest that male information seeking behaviour is often kept a secret). It is important to note that at times it is the practice of the medical institutions that limit their involvement. The practice of quick decision-making without the male partner in the room was found in our research as well (Bauer, 2014; Sándor, Vicsek and Bauer, 2017; Vicsek, Bauer and Szolnoki, 2019).

Thirdly, literature shows that the new father role also involves greater *physical presence and partaking in more medical visits*. Research also illustrates that many times men would like to participate more, but workplace practices are still many times adhering to the traditional breadwinner father roles – and not provide time off for fathers during pregnancy (Reed, 2012). Even though the literature shows that participation at foetal ultrasounds can have an important reinforcing and solidifying effect on the parental feelings of men – and through this can challenge the traditional gender role of women being the only knowers and protectors of the foetus (Reed 2009, 2011, 2012; Vicsek, Bauer and Szolnoki, 2019).

3.4.3. Infertility – gendered blame, unequal burden, gendered reactions to treatments

“As genetic technologies become more widely available, understanding their public acceptability and social implications is of increasing interest and importance to scientists, health professionals, policy makers and ethicists” (Doolin and Motion, 2010, p. 669). Nimkoff (1951) and Edwards have predicted that biological innovations have a direct effect on family, “changing the very constitution of humankind” (Edwards, 1991, p. 349). A pronatalist “restricted view of the family has profound implications for people’s access to reproductive treatment services and the consequent ease or difficulty of increasingly large numbers of people in establishing a family themselves” (Langdridge and Blythe, 2001, p. 47).

We can unequivocally state that, “the availability of reproductive techniques has fundamentally changed the ways families are created” (Bartels, 2004, p. 3). In many countries not only couples who have infertility problems can take advantage of these technologies (though not all have the opportunity in all countries, and with state funding). ART-s have resulted in the creation of family types that otherwise would not be existent (Fasouliotis, 1999). As a result, much broader group are able to become parents than without the technology (Langdridge and Blythe, 2001). As described above, the traditional father role is challenged by modern day parenting roles, where a much more active father role is described (Dick, 2011; Reed 2012). In fact, I will argue that partaking in medically assisted reproduction processes ideally also fades this distinction, the regular visits and participation in treatment cycles may lead to a more involved father role, when this made possible by the system.

Family formation is socially considered a desirable and ceremonious life-event, especially in societies with traditional, pronatalist views like Hungary. 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 a crucial step in the maturation (Reed, 2012) and thus involuntary childlessness has been known to have significant and irreversible social and psychological consequences (Golombok, 1992; Elek 1996, Verhaak et al., 2006). Infertility and involuntary childlessness are

globally perceived as a unique form of tragedy and loss. On the next pages I will look at how perceptions of infertility are gendered, especially in pronatalist societies.

While infertility of a couple can be caused in equal percentile because of male and female infertility (Anderson, 2005; Bayer, Alper and Penzias, 2017; Meniru, 2004), yet it is perceived differently, society has a gendered view of infertility, taking a different behavioural approach to male and female infertility (Becker, 2000). We experience an unsolvable paradox here – traditionally society sees childlessness as the fault of women – for centuries women have been marked by the “infertile” label, even though biologically the cause of the medical problems can originate equally from men or women.

Ettore (2002, p. 83) argues that there are higher stakes for women, their bodies are ranked based on their “genetic capital” – a.k.a. their “breeding potential”. Corporeality seems to be more salient in the context of women. Women with infertility problems are said to have “bad genetic capital”. Rapp (2000) also argues that this genetic responsibility is highly gendered, and women are the ones who take responsibility for the conception and the “production of a quality foetus” (Reed, 2012, p. 98). This responsibility stays with them throughout the stages of pregnancy, women are the caretakers that must watch themselves and follow strict medical orders. This is especially the case for pregnancies achieved by medically assisted reproduction (Becker, 2000; Szalma, 2021b).

Yet still empirical sociological and psychological research has shown that infertile women are more prone to sympathy, while infertile males experience less support and are more often the subject of ridicule, causing greater stress. Patients’ construction of and response to their own fertility is also divergent, gender specific, coping and dealing with infertility is also different according to dissimilar gender roles adopted by the patients (Peterson et al., 2006; Pottinger et al., 2006; Reed, 2012).

Social scientific attitudes towards new reproductive technologies have not been unified. Initial feminist reactions were twofold, some were optimistic, but most relevant authors expressed concerns over the then novel reproductive technologies. Michelle Stanworth (1987) points out: the debate has mainly centred around three ranges of issues: focus on the ethical and legal consequences related to the ‘use’ of embryos; the changing structures of parenthood and families and the third being what feminist writers have brought forth. Feminist literature has been concerned with the effect of the technologies

on the lives of women, both in the practical and a philosophical nature. Feminist scholars were one of the first to form opinions on assisted reproductive technologies, but this does by no way mean that they agreed on the forthcoming consequences or implications. Aspects of these debates are still active, focusing on the effect of innovations in reproductive technologies from a gender related perspective. Some saw the technologies beneficial for the female gender, while others discredited them as not only adhering to strengthening the inequalities between men and women, but also stripping women from their possession of motherhood. (e.g., Corea 1988, Mies, 1987).

Strands of (mainly earlier) feminist theory saw medically assisted reproductive technologies as a threat to women, and to the relations of motherhood – taking this away from women. Their thinking was that the assisted reproduction will further subjugate women and stabilize paternalistic power relations - ‘have increased potential for others to exercise an even greater control over women’s lives’ (Stanworth, 1987, p. 4). Stanworth argues the technologies can in fact become a tool for domination both through the dominant male representation in politics and healthcare. Dworkin, Oakley and Pollack Petchesky also saw the rise in medically assisted reproduction as a way to control the female body through the reproductive system, depicting the process as the farming model’ and the ‘reproductive brothel model’ (1983), while Naomi Pfeffer instead emphasized how these technologies can be a new venue for consumerist exploitation.

Empirical evidence has not conclusively supported the thinking that the technologies have been a tool for the further subjugation of women in the long term, because of the nature of technology itself. Exploitation of women with the use of reproductive technologies do come up in other contexts though. There are some fierce critics of surrogacy and the concept of reproduction tourism (Cherry, 2014, Deonandan, Green and Van, 2012). The commercialization and consumer exploitation discussed by Pfeffer emerges in different contexts. Birenbaum-Carmeli (2003) is also critical of the global inequality of access to reproductive technologies, highlighting intersectional inequalities. Also, a large corpus of research has focused on ethical dilemmas and solutions connected to assisted reproduction (i.e., spare embryos, oocyte and gamete donation, vitrification). From a gender role perspective, the main dilemma is that women are still having the burden of genetic responsibility, they sometimes making these morally conflicting decisions with limited partner involvement – as they can be categorized as

“women’s issues”. The ethical debates about embryos will not be detailed in the dissertation, due to its stand-out nature, abundant literature and previous publications of the dissertation’s author (Sándor, Vicsek and Bauer, 2017; Vicsek, Bauer and Szolnoki, 2019; Vicsek, Sándor and Bauer, 2021).

Another, more optimistic line of feminist thinking for example the works of Firestone (1988) emphasized progress and the liberation and the opportunities instead. In their views these new reproductive technologies were more help for women who wanted to conceive, and an effective way to overcome the physical, psychological and social burdens connected to infertility and involuntary childlessness.

3.5. Online science communication

3.5.1. Health and illness online

According to Conrad and Stults (2010), the Internet has changed the illness experience, making it both a private and a public experience through the availability of information and online health and illness communication. The past decades have brought forth a myriad of research topics and methods examining the role of the Internet and online communication (Sloan and Quan-Haase, 2017). An influential segment of these inquiries dives into understanding online activities connected to health and illness. Internet research on the topic of health and illness is also highly diverse stemming from an interest in health inequalities, online health-related searches, digital health applications, etc. (Dol et al., 2019; Smailhodzic, Hooijsma, Boonstra and Langley, 2016).

The rise of social media communication has in many ways changed how we gather information or communicate about illness-related issues or questions. Based on Kaplan and Haenlein (2010) social media consists of internet-based applications that rely on the technology and ideology of Web 2.0 and thus have the capacity to publish and disseminate individual user-generated content to a mass audience. Both public and private social media has grown to be the central venue of opinion dissemination and social debate (Sloan and Quan-Haase, 2017; Zhong, 2021). Online communities offer opportunities in health information dissemination that earlier influential communication channels (e.g., television, radio or print) could not (Cotton and Gupta, 2004; Hardy, 1999). In addition, Cline and Haynes (2001) argue that health information seeker patients tend to trust online information more (view it as having more credibility) than other mainstream media accounts⁹.

Entering the online discursive space provides an unparalleled opportunity for users to communicate about even such intimate topics as illness and health without feeling exposed and ashamed (Kozinets, 2020). Never before have patients had such an opportunity to communicate freely without the fear of stigmatization and achieve social contact, all the while remaining anonymous (Bauer, 2017c; Forgie et al., 2021;

⁹ As desinformation about the pandemic is rising the perceived credibility of information sources (especially about Covid-19) is in flux.

Smailhodzic, Hooijsma, Boonstra and Langley, 2016; Zhong, 2021).

Thus, the online sphere also presents an unprecedented opportunity to understand the perspective of patients and their families, “*Online illness forums are ready-made laboratories for making observations and drawing conclusions about experiential patterns or trends based on a large collection of personal narratives.*” (Barker and Galardi, 2011, p. 1353). The above quote from Barker and Galardi sums up the main angle of the study of online science communication adopted in this thesis research. The innovative methodological solutions to study these unique populations and communities are discussed in greater detail in the subsequent Data and Methods part of the dissertation (Chapter 7).

The use of internet discussion groups is a phenomenon that has implications and consequences that have recently been examined in detail (a rather large corpus of scientific literature is now dedicated to the issue) (e.g.: Elvey et al., 2018; Langer and Beckman, 2005; Pittman et al., 2017; Victoria Diniz et al., 2018). Multiple studies have concluded that online users talk about subjects similarly to in 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 (Wallace, 2006; Sloan and Quan-Haase, 2017).

Among many functions of internet communication, one is to offer help and support to others with similar problems. One example of this is the online-support groups, of which health-related issues are a common topic (Wallace, 2006; Zhong, 2021), the role of online communities will be detailed in a subsequent subchapter of the dissertation, highlighting patient motivations, benefits, and potential dangers for misinformation of these groups, finally introducing how the online patient communications (information gathering and peer advice and support) impact lay expertise and the dynamics of the doctor-patient relationship.

3.5.2. The roles of online health communities – information and support

Smailhodzic, Hooijsma, Boonstra and Langley (2016) argue that since the emergence of social media, patients have been using the technology for health-related reasons. The focus from more traditional online sources and communities such as forums

and discussion groups has been augmented by social media channels, especially open and closed Facebook groups. They posit that social media has an important role in complementing information received from treating professionals. Evidence shows that Internet health information seeking does not supplement offline seeking from treating doctors (Zhong, 2021)

Online participation can be both an observational and an interactional patient action (Conrad and Stults, 2010), mirroring the two main purposes of online patient communities, namely information dissemination and providing support. According to Pitts (2004), the online space can be interpreted as a virtual library for information and also a means for better understanding medical language. She also posits that for many the Internet is a “beacon of hope” both due to vital information and community experience.

According to Forgie et al., (2021), 80% of Internet users seek health information online. The aim of health information seeking per definition is: “*to reduce uncertainty regarding health status*” and “*construct a social and personal (cognitive) sense of health*” (Tardy and Hale, 1998, p. 338). As depicted earlier in the thesis, historically the primary source for such information was the professional, the doctor, and only recently has the access for lay patients to acquire a vast array of medical information through online channels become available. This opportunity has changed the nature of lay-professional relationships, and the role and status of expertise as detailed in subsequent part (Nichols, 2019).

Based on conclusions from Cotton and Gupta (2004) there are characteristics that separate online and offline health information seekers. Aside from the traditional digital divide, other factors are to be considered: many are not comfortable confronting professionals with their questions but are eager to discuss them with peers, while there are those, who value the opinions of peers more.

Internet communities provide a way for a group of peers to communicate with each other without ever meeting (Robinson, 1991). Health-related online forums present a special segment within online forums, because of the nature of the discussed topics. Tanis (2008) has reported that the main reasons for using health-related forums online were the following: information gathering; emotional support; inclusion; supporting others; convenience; passing time. More recently, Smailhodzic, Hooijsma, Boonstra and

Langley (2016, p. 16:442) in their review conclude that patients from a rational perspective, mostly join online communities because they find that their emotional and informational needs, and to “*bridge the gap between traditional health information about their condition and everyday life*”.

While the greatest emotional drive is seeking out social peer support (Coulson, 2005), according to Fair (2010) online communities also have a role in developing illness identities, uniting them, and providing a sense of collectiveness, alleviating isolation. The types of support can be categorized as follows: (1) emotional support; (2) esteem support; (3) information support; and (4) network support (Bartlett and Coulson, 2011; Chiu and Hsieh, 2012; van Uden-Kraan et al., 2008). Smailhodzic, Hooijsma, Boonstra and Langley (2016) have also added that online discussion communities offer a safe environment for emotional expression as well as social comparison. Latter merges emotional and informational prongs as patients use others’ stories as a comparison (or measurement) for their own conditions, simultaneously learning from them and utilizing them to cope emotionally. Studies conclude that online peer support leads to patient empowerment; enhanced subjective well-being; and enhanced psychological well-being; improved self-management and control (Smailhodzic, Hooijsma, Boonstra and Langley, 2016). Online discussion group advice also has its problems, due to the dissemination of misleading information, which is solely based on personal experience and lacks medical bases (Cotton and Gupta, 2004),.

Online support groups provide a specific role in relation to women’s health issues, especially in questions regarding conception, pregnancy, or infertility (Malik and Coulson, 2008; Muhammad, 2011; Sormunen et al., 2020). Bundorf, Wagner, Singer and Baker, 2006 state that women are more active in online health information seeking and are more likely to believe the information found online. Additionally, Bunting and Boivin (2007) have argued that women are those who are more active in seeking advice both online and offline about their fertility problems. The obtained level of knowledge was found to be an important indicator in if the couples’ decision to partake in medically assisted reproduction.

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 (Wallace, 2006). The effect of social stigmatization regarding childlessness and

infertility may lead to subjects feeling that these discussion groups are the only place to talk freely about their fears and hopes and analysing such conversations will allow the researcher a view at the subjects' unveiled and truthful perceptions, without the shackles of social constraint (Berger, Wagner and Baker, 2005)

3.5.3. The effect of the Internet on the doctor-patient relationship

Online discussion communities (including both traditional and social media sources) impact the doctor-patient relationship. Smailhodzic, Hooijsma, Boonstra and Langley (2016) have stated that online knowledge can aid patients by the means of fostering their autonomy, empowering them in the traditionally hierarchical relationship.¹⁰ Barker and Galardi (2011, p. 1353) have argued that “*not only does connectivity give laypeople the moral authority to challenge scientific expertise, it also provides them with the means to do so*”. Moreover, the online sphere allows for the widest range of patients to access health-related knowledge alongside peer and expert advice – allowing for significant knowledge accumulation by the lay public. As it has been pointed out that the online space is the main source for lay patients to access and disseminate knowledge, with the main function of online communities being this type of peer informational base (Fair, 2010).

The depth of this online acquired factual knowledge, combined with contextual, lived experiences have contributed to the rise in lay expertise and lay expert patients. This is in line with the tenets of Myskia (2007)¹¹, who explored the criteria for lay expertise and how knowledge is the foundation for questioning authority. Conrad and Stults (2010) posit that the new information does not replace previous knowledge, but it is no longer the sole property of experts, which can lead to reduction in their authority, a tendency for a less asymmetrical, hierarchical relationship.

The effect of online participation is not monolithic, both positive and negative tendencies can be observed (Ayers and Kronenfeld, 2007; Nettleton et al., 2005). Benefits of these changes include more equal communication, better understanding of medical

¹⁰ The dynamics and the changes between the doctor-patient dyad have been detailed at length in Chapter 3.3. of the dissertation both from the viewpoint of medical sociology and the perspective of biopolitics and biopower.

¹¹ Lay expertise and its roles are detailed from a Science and Technology studies perspective in Chapter 3.2. of the dissertation.

terminology and treatment, patient confidence. Tan and Goonawardene (2017) argue that online information-seeking behaviour can improve the relationship and its interactions, as communication can be more seamless, the patients feel more in control and engaged in their decision-making.

Smailhodzic, Hooijsma, Boonstra and Langley (2016) on the other hand argue that online information seeking, and peer-support may also present challenges and tensions. There can be a decline in patient compliance and an increase in switching professionals based on peer advice (Malik and Coulson, 2010; Rupert et al., 2014). Moreover, the health information sought from online sources often poses a problem of credibility as more and more unvalidated misinformation reaches patients (Cotton and Gupta, 2004; Nichols, 2019). Tan and Goonawardene (2017) emphasize the potential risks of Internet-informed patients practicing self-diagnosis and self-treatment, a shift in the informational balance the professionals are not yet prepared for.

Forgie et al., (2021, p.e25230) argue that if the issue is addressed properly the online sphere and social media can be used to “catalyze positive changes” in the dyad’s relationship, but “*Work must be done on the part of the physician and the patient to shift the physician-patient relationship toward one that is inclusive of the role that social media plays in health and that uses social media as a tool to promote health and well-being*”. New skills need to be adapted from the patients’ side as well, they need to continuously become more vigilant in the identification of misinformation or malicious disinformation.

4 Empirical background of research project

This portion of the research dissertation contains a selection of important empirical research and findings connected to infertility and assisted reproduction, introducing evidence from international and Hungarian inquiries. Highlighted very succinctly below are relevant stands of research that are reintroduced as reference points in the analysis and discussion part of the dissertation.

4.1. Experiencing infertility and childlessness from a psycho-social perspective

Besides the biological and medical aspects of infertility and involuntary childlessness it is important to consider the socio-psychological implications of the question. Prior to the overarching medicalization of health conditions, infertility was seen less as a treatable state (life-event or biographical disruption) and more as a punishment (in certain cultures a will of God) (Miall, 1994). Though viewing it as a medical condition or an object of fate diverges greatly there are some common socio-psychological traits. The empirical literature does not agree fully in the exact enumeration of psycho-social consequences of infertility, there are some common grounds.

One of the major consequences of infertility is the element of surprise that the patient may feel over losing control over their own body (Mathews and Mathews, 1986). Holter et al. (2006) claim that infertility is ranked as one of the greatest stressors in one can experience throughout the life course, according to synthesize research it is a stressor comparable to divorce, death in the family, or experiencing such terminal somatic diseases as cancer or HIV. Hungarian research has also suggested that coping with infertility has similar methods and ramifications to that of dealing with death (Mata, Boga and Bakonyi, 2001).

Based on empirical investigations stigmatization (even if it is the result of pity or sorrow) of infertility may induce isolation, especially in highly pronatalist and paternalistic societies, and patients' construction of and response to their own fertility is

also divergent, gender specific (Greil et al. 1988; Mata, Boga and Bakonyi, 2001)¹².

4.2. Experiencing medically assisted reproduction

4.2.1. Decision making about participating in medically associated reproduction

Due to the rapid development of these innovative technologies' prospects have changed for individuals and couples with fertility problems (McNeil, Varcoe and Yearley, 1990; Hudson et al., 2009). These methods include not only the medical possibilities, but several social and psychological methods as well (Peterson et al., 2006).

Just as childlessness, the decision to engage in or to bypass the use of these new technologies can be a difficult choice, and the literature agrees that decisions made to engage in treatment using medically assisted reproductive technologies, or omitting such solutions are complex and have several influencing forces, including both personal and societal elements (Becker, 2000; Rauprich, Berns and Vollmann, 2011; Zegers-Hochchild, 1999). Treatment decisions may raise interpersonal and emotional issues that can cause the patients significant distress (stigmatization and isolation), especially if the societal acceptance and support is low for the technologies (Beckman and Harvey, 2005; Peddie, van Teijlingen and Bhattacharya, 2005).

Strong mitigating factor for involvement may be the risks (both physical and psychological) of the treatment, but prior empirical research conducted by Becker (2000) found that in both women's and men's decisions these risks were weighed as small compared to the problem of infertility, remaining childless. In Hungary Vicsek, Bauer and Szolnoki (2019) also concluded that while ART-patients worry about the possible consequences or side-effects, their decision to seek treatment is mainly influenced by their ultimate goal of having a child.

A unique aspect of such lack of risk avoidance was also highlighted by Rauprich, Berns and Vollmann (2011). Based on their German survey results, they emphasize that the patients may not even be able to make reasonable and balanced choices, because of their yearning to become parents. On the other hand, Wingert et al. (2005) view some

¹² For greater detail see Chapter 3.4

choices to be consumer conscious based on qualitative content analysis of an online bulletin board for women.

It also must be taken into consideration that decision-making about medically assisted reproduction is also rather unique since it does not only involve one individual but are most frequently decisions of couples (Beckman and Harvey, 2005; Throsby and Gill, 2004), and can end up causing a stressful family event (Wingert et al., 2005). Reed (2009, 2012) on the other hand argues that most of the reproductive and genetic responsibility still burdens women, so in fact they are the most loaded with the challenging decisions.¹³

The opinion of the community and the society can potentially have an effect on how couples involved in the use of certain reproductive technologies cope with this state and see their infertility. The views of society on involuntary childlessness or the stigmatization of the status, being conceptualized as a deviant attitude may also affect on how the couple copes with the issue at hand. Infertility of a couple can be caused in equal percentile because of male and female infertility (MCHC, 2019) yet it is perceived differently (Franklin, 1995; Greil, Slauson-Blevins and McQuillan, 2010; Greil, McQuillan and Slauson-Blevins, 2011; Miall, 1994).

A review publication of Gupta et al. (2011) socio-psychological determinants are to be viewed when investigating public acceptance of controversial technologies (this work mainly focuses on risk perception). It has been reported that many couples feel a drive towards ART treatments because of their longing for children (Rauprich, Berns and Vollmann, 2011; Wennberg et al., 2016). Prior research has stated that risk assessment with regard to the treatments is often influenced by this desire. I suppose that in this manner also public opinion would have a more limited effect in the decision-making process but would affect how their treatment is perceived.

4.2.2. Psycho-social consequences of medically assisted reproduction

Research has also been conducted with women or couples utilizing medically assisted reproduction to study the psycho-social impact of the treatments. All findings point in a similar direction, namely that taking part in such a long treatment process

¹³ For greater detail see Chapter 3.4.

(where there may be several failed cycles or treatments) takes a serious toll on the psychosocial well-being of the seekers, it being both exceedingly stressful as well as emotionally demanding (Weaver et al., 1997; Verhaak et al. 2006). Mathews and Mathews (1986) have compiled the most frequently mentioned negative emotions: surprise, denial, anger, isolation, guilt, grief, depression, resolution. According to the findings of Verhaak et al. (2006) 20% of women reported feelings of depression six months after an unsuccessful treatment. Reports of feeling elevated levels of stress and emotional volatility was found during research done among women participating in internet discussion groups, focusing mainly on feelings of hope or despair and emotions of anxiety and frustration towards the health system and the feeling of objectification from members of the medical community (Becker, 2000).

The psychological reactions and adjustment levels vary greatly with respect to the outcome of the treatment as well as the examined time-period (short-term and long-term effects are different according to the literature, the patients show good coping in longer term) and the gender of the patient, the psychological research results showing large diversity (Cserepes et al., 2013; Cserepes et al., 2014; Holter et al. 2006; Verhaak et al. 2007). This is emphasized in research conducted by Weaver et al. (1997), who oversaw a series of interviews as well as survey studies on couples who have successfully conceived a child at the end of the treatment and also with couples who have not had a baby. The authors concluded that there were only few indicators that showed long-term psychosocial adjustment problems, but those were severe (this is contradictory to earlier findings of (Leiblum, Kemmann and Lane (1987) that reported significant differences among women with failed IVF treatments). Social stigmas connected to medically assisted reproduction were also relevant in certain more traditional societies (Becker, 2000; Birenbaum-Carmeli and Inhorn, 2009), along with some religious concerns (Doolin and Motion, 2006).

4.2.3. Health costs and risks associated with medically assisted reproduction

Aside from the introduced psychosocial consequences the treatments also have several physical implications for the patients. Many these are caused as a side-effect of the hormonal and other medications used during distinct phases of treatments. Some of the most common and often named side-effects are nausea, hot flushes, ovarian

overstimulation, abdominal pain, dizziness, depression, mood swings and insomnia. Multiple pregnancy and pregnancy loss are also risks that have to be taken into account. Some of the risks are even more complex and potentially dangerous (for example infections after insemination or harm to surrounding organs due to complications during punctation extraction (Meniru, 2004, Holter et al., 2006).

The patient is informed about all of these through the physician and is asked to sign a consent form before any procedure begins. Together with the psychosocial consequences the physical tolls induce a relatively large drop-out rate from the treatment (Verberg, Fauser and Macklon, 2008). As reported by treated patients the physical afflictions also caused severe emotional distress for the patients contributing to their feelings of powerlessness and isolation (Matthews and Mathews, 1987).

5 The Hungarian context of the research

The infertility treatment context has gone through significant changes throughout the duration of both the encompassing research project and the investigation at the core of this thesis. The following chapter will draw a timeline for these changes and pinpoint those issues are seen to have had considerable influence on both the data collection and the narratives and topic driving the online conversations. A distinct part of this overview will highlight those issues that had been quite salient earlier during the investigation period but by the publication of the thesis have been legally solved, and are gradually becoming parts of practice and procedure, and in time become a relevant part of the researched patient experiences.

The chapter will touch upon the following topics: (1) trends and tendencies of childlessness and involuntary childlessness in Hungary; (2) governmental communication, both formal and informal stances on infertility and treatment; (3) the legal context and its changes (controlling access and financing of various MAR treatments); (4) the Hungarian social attitude and its changes towards childlessness and infertility treatment (based on Hungary-focused empirical research results and conclusions).

5.1. Childbearing and childlessness in Hungary

Childlessness is still considered to be an undesired state in Hungary, where traditionally the state has encouraged couples to plan for and have multiple children. Hungary is considered a traditional society that places high emphasis on the values of family and sees children as a significantly important aspect of this traditional view on families (Kende, 2002; Sallay, Martos and Hegyi, 2015).

Using the Hungarian data from the Generations and Gender Survey, Kapitány and Spéder (2009) have concluded that only an exceedingly small portion of men and women (1,4% and 2,4%) would consider childlessness as an ideal situation. Not having children is considered to be a state that is very negative and thus should be avoided by the public

in Hungary (Kapitány, 2015; Kapitány and Spéder, 2019; Miettinen and Szalma, 2014; S. Molnár, 1999; Szalma, 2014).

Involuntary childlessness is less frowned upon and handled with greater compassion, in line with the international literature's empirical results (i.e., Miall, 1994; Mumtaz, Shahid and Levay, 2013). Infertility due to postponed childbearing because of women focusing more on higher education and establishing a stable career-path before family formation is less accepted, partly offering evidence of the unequalled gendered responsibility of reproduction in Hungary (Mumtaz, Shahid and Levay, 2013; Paksi and Szalma, 2008; Szalma and Takács, 2018; Takács and Szalma, 2015). Yet the tendencies show that the rate of childless women and men is rising within society, showing different patterns based on location, religiosity, career goals etc. (Kapitány, 2015). In the following subchapter these tendencies will be examined and explained shortly.

If we look a bit back historically, we can see that before the regime change it was quite uncommon for women not to have given birth at all, but since the 1990-s childlessness has increased. This phenomenon is not unique to Hungary, or even the region (Sobotka, 2017) – decline in fertility rate has been registered throughout Western societies (Anderson, 2005; Miettinen and Szalma, 2014, Sobotka, 2017). The age when women are having their first child is rising as well, and many women only have one child throughout their life-course (HCSO, 2017; Kapitány, 2015).

Recently according to Sobotka (2017) and Kapitány (2015) the rate of childless women is also showing a rising tendency. While the 2001 census showed that 7,8% of women above the age of 45 were childless, the number in 2011 was already 11,2 % (Kapitány, 2015). Escalating trends can also be seen in the 2016 micro-census, where 56% of women between 25 and 36 had not yet given birth according to the Hungarian Central Statistics Office (HCSO, 2017). Early statistics have also shown that the 2020 Covid-19 pandemic has not resulted in the expected 'baby-boom', but less children.

These registered declining tendencies are despite the pronatalist attitude and policy incentives of the Hungarian conservative government, which will be introduced in a subsequent part of this chapter about the Hungarian context. Reasons for delaying childbirth include difficulty of establishing a stable partnership (that is considered an especially important factor by Hungarians) (Szalma and Takács, 2014, 2015), and

creating sufficient financial grounds.

Involuntary childlessness in Hungary is lower than other EU countries according to Eurobarometer statistics (Miettinen and Szalma, 2014), so according to the data, Hungarians wish to have at least one child in the course of their lives, and Hungarians also overwhelmingly agree that it is imperative for a woman to have at least one child to live a happy life (Szalma, 2014). In this regard, we can state that the value of children (VOC) is quite high in Hungary in all of the dimensions defined and investigated in the VOC framework (Aycicegi-Dinn and Kagitcibasi, 2010).

Partly accounting for involuntary childlessness is the decline in conception capabilities in both women and men. The rise in fertility problems can be attributed to changes in life structures, more and more women participating in higher education and career-building (Paksi and Szalma, 2008; Szalma and Takács, 2015), but other life-style factors such as escalated levels of stress, and unbalanced biorhythms, and even pollution, all point to the fact that involuntary forms of childlessness due to infertility or other conception problems is likely to increase (Meniru, 2004; Anderson, 2005; Soini et al. 2006, Bayer, Alper and Pezinas, 2018).

These tendencies result in a rather large, and significantly increasing portion of the childbearing age population experiencing troubles with conceiving a child naturally. In 2012 it was reported to be 10-15 percent of couples were estimated to need some sort of infertility treatment, and this rate increased to 15-20 percent by 2019 respectively (HCOG 2012; MHCH, 2019). Yet when comparing the number of children born in Hungary and other EU countries, we can see that the number is lower – between 1,5-2% of Hungarian babies are born via IVF cycles, while this rate for other EU countries is between 1,2-4,5% (MHCH, 2019). Europe is leading in the world with almost 50% of IVF cycles being performed here¹⁴, Spain registering the most completed cycles followed by France, Germany, Italy, and the UK (ESHRE, 2020).

¹⁴ The ethical dilemma of the uneven global access to infertility treatment is not the topic of this thesis, but it is an important issue that must be addressed, as access to IVF had previously shown a growing tendency, but now slowing down (ESHRE, 2020).

5.2. Pronatalist governmental rhetoric

For over the last decade the right-wing conservative Hungarian government has portrayed a pronatalist approach both in rhetoric and in applied social policy (Sági and Lentner, 2018; Szikra, 2018). From 2010 on, conservative politicians and organizations have been emphasizing the importance of traditional family forms and values, along with voicing that Hungarian women should (almost as patriotic duty) have more children and start family formation at an earlier age. In line with the pronatalist thinking introduced in detail in an earlier chapter of the dissertation, much of the responsibility for procreation, and family formation is placed on women, who throughout the past decade have been laden with being the primary bearers of genetic responsibility.

Pronatalism, the emphasis of having every child born, and the support of larger families, adhering to traditional gender roles are at the forefront of governmental communication at the highest levels. In following I will first give examples of the pronatalist, traditional family supporting governmental rhetoric, then subsequently show how these ideologies and values are adopted into social practice through social policy measures and legislation. The pronatalist approach is embedded in the nationalist ideological thinking that it is imperative for more Hungarian children to be born, otherwise with the aging population and insufficient population growth, the Hungarian nation and its traditional core values are at risk (Szikra, 2018; Spéder, Muninkó and Oláh, 2020). This rhetoric is represented at the highest levels including Katalin Novák, Hungary's minister of state for family, youth, and international affairs, and Viktor Orbán, Hungary's prime minister.

In 2012, at the Demographic Conference the low fertility and birth rate was pronounced one of the greatest challenges Hungary is facing in the 21st century, and since then this idea has influenced political rhetoric and legislation alike. Traditional family model and the special moral status of the embryo was defined in the new Fundamental Law, securing the pronatalist, traditional view in its Preamble.

Subsequently a number of policy measures were introduced all aimed to encourage procreation and establishing large, biologically related, two-parent multi-child families, with special preference that the heterosexual parents be married. These incentives include

tax reductions and tax deductions, life-long tax exemption for women who have given birth to at least four children, a low interest loans were also made available, and debt reduction is also a possibility for those families that raise two or more children. These are along with financial support for purchasing adequate vehicles for large families. As there is an insufficient number of nurseries, the government promised to create over twenty thousand places by 2022. The efficiency of these measures is critiqued, most critics stating that these are not adequate incentives for population growth, and in addition essentially benefit a narrower, selected segment of more well-off society, and does not support increase in the number of children universally (Szikra, 2018).

5.3. Changing legal context

Parallel to the above-mentioned measures, changes in the legal context regarding assisted reproduction were also implemented (National Human Reproduction Program, a comprehensive program to support infertile couples, including the nationalization of six clinics, making their offered treatments free, including all medications, testing (About Hungary 2019). As discussed subsequently, these changes also mirror the pronatalist and traditional family form supporting approach – granting generous benefits for those selected, all the while restricting access to other social groups. Recent changes are introduced below.

The legal framework regulating assisted reproduction has been changed throughout the course of the research project. It is important to look at both the original and the current legal practices as both have been the law and have influenced the context of assisted reproduction during the examined research period. The changes initiated in the legal framework are in line with the pronatalist philosophy and communication of the conservative government, which prefers the traditional family model and emphasizes the importance of biologically related children. As we could see above this is not in contrast to Hungarian public's attitude towards children and childlessness.

The legal framework regulates who is eligible for treatment, and for whom these treatments are financed. As IVF cycles initially have quite a prohibitive cost, the governmental financing for them is quite important when looking at accessibility. In this sense the original regulation was also quite generous compared to other countries' regulations, and as we will see the financial burdens of access have basically been lifted

in 2020. But parallel to the financing of five IVF-ICSI treatment cycles and many of the medications involved with the process, access to assisted reproductive technologies has been limited to those social groups the government has prioritized with other forms of social policy as well. The new regulations are restrictive in the sense that it prioritizes married, heterosexual couples and restricts access to homosexuals, and single and older women.

In Hungary the main source of the legal norms on medically assisted reproduction can be found in a specific chapter in the 1997 Health Care Act (CLIV) and in the Law CLXXXI of 2005. According to Langdridge and Blythe (2001) while the technologies allow solutions that are considered controversial the role of the legislation is to keep this in order, to legislate the traditional concepts. The regulation strongly supports the traditional family model, and severely limits the possibilities to seek assisted reproduction. Access for medically assisted human procreation according to the legal regulations is allowed to married couples, persons in a civil law marriage with parties of a different sex, infertile and aging single women.

Prior to 2020 modification, assisted reproduction could be financed two ways in Hungary. The couples could pay for the procedures for themselves (self-funding) or there is a certain number and types of AR that infertile couples are eligible for state funding through the National Health Insurance Fund Administration (NHIFA). Eligibility is regulated in the Act CLIV of 1997 on health and its later modifications. The funded procedures are regulated and enumerated in the Ministerial Regulation 49/1997 (XII.17) and its later modifications. The number of funded inseminations is 6. The number of state-funded IVF-cycles available for couples (and eligible single women) is also six up till the conception of two children. The medications that are part of the IVF-cycles and other AR treatments were supported, but not fully financed (up to 70% financed).

In 2020 six infertility clinics were nationalized, and both the cycle and the medication treatment costs became state funded (1011/2020 (I. 31.)). This was an important reduction of assisted reproduction costs as some of the special medications had high prices (especially those involved in the hormonal stimulation). The cost of the individual drugs (even with the 70% support) had ranged from 1 300- 57 000 HUF (based on the price list provided by National Health Insurance Fund Administration valid from January 1. 2019). For those who do not have insurance or have already participated in the

state financed cycles the costs of assisted reproduction are extremely high. Different clinics also have visitation and registration fees that also may exceed 15 000 HUF. If the couple decides to fund the treatments themselves the cycle itself (not including the freezing and storage of the spare embryos) is between 280 000 and 440 000 HUF depending on the exact treatment (based on the pricelist available at the website of the institutions).

While the current financing frame is indeed generous, and in line with the pronatalist sentiment, treatment costs are not the only items that are to be taken into consideration, which may result again in skewing the scale towards those patients participating, who are better off financially¹⁵. Travel costs and time off from work can still pose significant burdens on the patients. Over half of the facilities performing assisted reproduction treatments are in Budapest, the rest are in other large cities. Accessing them thus can pose a relevant problem for those couples, who live in villages, even though the travel expenses are in some cases refundable through the NHIFA. Moreover, prior to the IVF or other AR treatments there are a large number of tests and examinations that the patients must go through (HCOG, 2012; MHCH, 2019). All these precisely timed events require certain time off work for the examinations themselves and in many cases a longer resting period for the women. Missing work, or the inaccessibility of working from home is also more the own of couples having less stable financial backgrounds.

Based on patient reports and information from fertility clinics, most of them have a lengthy waiting list for the procedures. While this is a problem for most sectors in the Hungarian health care system, the factor of time is of utmost importance in assisted reproduction – many patients have expressed worries about running out of time in general, but also because of lengthy periods spent on waiting lists for procedures (Bauer, 2014b).

In some institutes there was a significantly higher waiting period registered for those patients, who have relied on the state for the funding and do not have the considerable resources needed to self-finance the treatment. Patient accounts have stated that there could be an extra six month to a year difference when not choosing to have the state financed assistance, even in the same institution. If the patient chose to pay for the full treatment, they gained time and have less stress during the waiting periods before and

¹⁵ Implicit evidence of this is the higher number of twin births of couples who are better off financially (Drjenovszky, Hegedűs and Pári, 2013)

between cycles. Patient accounts have also told us that when having participated in both types of treatments, they felt that private funding also bought them better care and facilities (Bauer, 2013). This statement should be handled keeping in mind that these were subjective reports on the matter and the emotional state of such patients may have induced elevated negative responses due to failure to conceive. Nevertheless, this discrepancy was an important theme of investigation during a substantial portion of the investigated timeframe.

5.4. Hungarian social attitude and its changes towards childlessness and infertility treatment

As mentioned in an earlier introduction, sociological investigation on assisted reproduction has a brief history in the Hungarian sociological community. Hungarian attitudes or experiences regarding assisted reproductive technologies have been researched in detail by Szalma and colleagues, and Vicsek and colleagues. Prior, looking at the social acceptance and knowledge of the technologies using both quantitative and qualitative methods, while latter team focused foremost on investigating experiences of those partaking in treatments and looked less at acceptance and more at lived experiences, such as complex ethical decisions, moral dilemmas.

As discussed above majority of Hungarians view childlessness as a state that should be avoided, and an obstacle in the way of women's happiness. As introduced, the value of children is high, and the traditional family model is what is foremost supported by Hungarians. Szalma's (2014) analysis of items from the European Value Survey in 2008 shows that the majority (93%) of Hungarians agreed with the statement that children need to live with both parents to grow up happily. While both parents are considered vital to child development, an interesting result from Szalma's qualitative work was that participants did not connect infertility and treatments to men. This one-sided emphasis of women is not uncommon in international sociological literature on infertility (e.g., Greil, Leitko and Porter, 1988; Mumtaz, Shahid and Levay, 2013), but is definitely not supported by medical facts, which attribute couples' inability to conceive equally to both sexes (Anderson, 2005; Bayer, Alper and Pezinas, 2018; Soini et al., 2006; Meniru, 2004). The gendered burden of reproductive responsibility is detailed in an earlier theoretical

chapter of the dissertation.

Turning to the detailed introduction of research on public acceptance of medically assisted reproductive technologies, we can state that similar to international literature, the timing (when?) and cause behind (why?) of utilization of assisted reproductive technologies influences publics' attitudes. Quantitative results show that there is an overall support for medically assisted reproduction in Hungary (Szalma, 2014; Szalma and Djundeva 2020; Szalma and Bitó, 2021; Závecz, 2017).

The results from Szalma and colleagues also unveiled that there are differences in attitudes based on socio-demographic factors. According to Szalma's (2014) quantitative findings main influencers of attitudes are micro-level factors. As Szalma (2021b, p.15) writes "these results also show that socio-demographic variables have a considerable influence on attitudes towards ART, for example: gender, age, religiosity, education, and number of children". Younger women have shown the most accepting attitude towards assisted reproduction, while older generations are less open. Increase in educational levels parallels higher acceptance, but unlike in other European countries monthly income did not prove to have significant effect in Hungary. Based on Závecz (2017) these results were supported, the 2017 survey's findings show that religion created the deepest caveat, but still 75% of those who identified themselves as religious had a positive outlook on IVF. (It is important to note though that Závecz's study was conducted in the midst of the debate about infertility treatment after András Veres catholic leader deemed medically assisted reproduction unnatural and a sin publicly. The emotional volatility of immediate social responses could have skewed the results).

Qualitative analysis from Szalma shows a more nuanced spectrum of attitudes ranging from supportive to dismissive. Those with a positive outlook on the subject see assisted reproduction as a way to help infertility women in achieving their goal for family formation and becoming biological mothers (Závecz, 2017). The analysis of interviews (with a sample of involuntarily childless women) has pointed to how participants framed assisted reproductive technologies as beneficial tools to overcome the biological barriers of infertility. An interesting discrepancy in the attitudes was identified: while the participants were accepting of the technology and had an overwhelmingly positive outlook on assisted reproductive technologies, when asked if they would use the technologies to help their own conception, they proved to be more cautious and reluctant.

This is understandable considering the emotional and physical consequences of assisted reproduction cycles (Holter et al., 2006; Verberg, Fauser and Macklon, 2008; Verhaak et al., 2006). The qualitative research also concludes that older women showed more critical attitudes toward ART and showed greater negative dispositions towards childless women (emphasizing career goals are responsible for postponed childbearing). According to notions of Szalma (2021b) those belonging to the older cohorts and were “*who was socialized according to a standardized, socialist life course misinterprets the postponers’ attitudes and the spread of ART as a consequence of the life choices of career-orientated women*”.

Another prong of Szalma’s qualitative research involved focus groups, the results show that again the attitudes were supportive (this was true across all groups, having diverse participants), and some participants were also willing to choose assisted reproduction if needed. Szalma concluded that as younger people in her Hungarian sample tend to be more open, which supports findings of other international studies about towards new technologies (Frewer, Howard and Shepherd, 1998) and especially regarding new genetics (Jenkins et al. 2001; Doolin and Motion, 2010; Sharp et al., 2010; Gaskell et al., 2017), this can help explain their more favourable attitudes, yet she also notes that younger women seemed more reluctant to participate in assisted reproduction themselves. Szalma argues that this can be linked that in their case having children or utilizing assisted reproductive technologies are less urgent matters. While attitudes towards couples’ infertility treatment was supportive, participants were less united in supporting its availability for single and older women (the support declined further in older cohorts) and support for non-heterosexuals was even lower in the focus groups.

Moral dilemmas regarding spare embryos were investigated by Vicsek and colleagues (including the author of this dissertation). Results show that IVF patients take on a more pragmatic attitude and put successful conception at the centre of their lay moral reasoning (Vicsek, Bauer and Szolnoki, 2019; Vicsek, Sándor and Bauer, 2021). Ethical considerations regarding spare embryos are less dominant based on patient interviews, with many participants having little knowledge about what options they have regarding embryos, highlighting some problems in communication at infertility clinics (Bauer and Pálóczi, 2018).

Knowledge about medically assisted reproduction was investigated by both teams,

and both qualitative and quantitative results show that there are some gaps in knowledge both related to fertility and technology (Vicsek, 2018; Szalma, 2021b; Szalma and Bitó, 2021). These misconceptions or holes in understanding could influence acceptance and attitudes and should be investigated further.

6 Research questions

The theoretical and empirical literature review has demonstrated that understandings of infertility and medically assisted reproduction is a controversial and ever-evolving sociological issue, which should be examined from many perspectives, using diverse approaches inspired by a myriad of theoretical fields adapted for the Hungarian social context. It has also shown gaps that can still be filled by introducing new sociological theoretical and methodological approaches underpinning studies¹⁶.

The concrete research goal of this dissertation (embedded in its parent larger exploratory research project) is to shed light on infertility and medically assisted reproduction experiences and understand them in Hungarian social, cultural, institutional, and technological contexts. The theoretical framework of the thesis lays at the crossroads of four distinct approaches, grabbing inspiration from science and technology studies, medical sociology, gender role theory and the field of online communication studies¹⁷. This venture is taken on foremost by utilizing a relatively new online qualitative methodology, netnography, with its findings augmented by more traditional qualitative patient and expert interviews¹⁸. With all the above taken into consideration the explorative research questions of the thesis can be phrased as follows:

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. It aims to unveil what are the focus points and discussion topics salient to the online participants. By the thematical analysis of these messages the emotional drivers will be explored, along with the most important semiotic expressions. The section also augments the online narratives with those identified in the offline qualitative interviews to explore how the two different methodological approaches compare.

¹⁶ Throughout our OTKA financed research project K108981., our team has looked for relevant ways to fill these voids, and as a result, there have been papers published using STS or medical sociological and bioethical based approaches (Bauer, 2014; Vicsek, 2018; Sándor, Vicsek and Bauer 2017; Vicsek, Bauer and Szolnoki 2019; Vicsek, Sándor and Bauer, 2021, Vicsek, Király and Kónya, 2016).

¹⁷ The details of the theoretical foundations of the dissertation are introduced in Chapter 4.

¹⁸ The background and techniques of netnography are described explicitly and in detail in the subsequent 'Data and methods' chapter (Chapter 7) of the thesis.

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

This second research questions looks at accumulated knowledge foremost from a science and technology studies perspective, to see how lay expertise is represented and how it can be identified. The question also deals with open source and experience based, contextual knowledge. 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.

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. 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 described in the medical sociology chapter. The analysis here aims to reflect on the agency patients attribute to themselves and the professionals, and how they interpret these dynamics.

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. It looks at how mechanisms of pronatalism and gendered prenatal roles are present throughout the narrated patient pathway.

7 Data and methods

The following chapter is dedicated to introducing the research methods of the dissertation. The methodological frame of the thesis lays in a unique connection of online and offline data. Three distinct qualitative methods are adopted throughout the thesis research – 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. This decision to emphasize one of the methods lays in practical considerations, not to make the dissertation incomprehensibly lengthy.

The introduction to data and methodology is structured as follows. First the chapter focuses on the benefits of the qualitative research paradigm, then has a brief introduction of the advantages of multimethod qualitative inquiry, and how the introduced design is harvesting from the benefits of both active and passive qualitative research methods. This part is followed by a detailed description of the research design and process. Introduction of netnographic research approach is followed by a birds-eye view of how qualitative interviews complemented the methodological design of the research. Netnography is portrayed in greater depth, because as of yet its use is less widespread in the Hungarian sociological community. Sampling strategies, and imminent ethical considerations for both methodologies are discussed. The chapter concludes with an introduction to the approach of thematic analysis, and its analytical roots of grounded theory.

7.1. The qualitative research tradition

Data for this research will be gathered primarily with the use of qualitative methods. Relying on qualitative approaches enables us to get an in-depth, well-rounded assessment of the complex lived experiences of medically assisted reproduction.

Qualitative inquiry in general provides the researcher with an opportunity to get closer to the participants' subjective opinions, experiences, and views on the world (Vicsek, 2006). This type of understanding was coined by Wilhelm Dilthey as 'Verstehen' ('deep understanding'), which allows the researcher to develop a closer and

contextual grasp that is required of such a complex issue as the one at hand and differs significantly from the method of natural sciences.

As Ritchie et al. (2014) argue: the lived experiences of subjects are of main significance, and that these are always influenced by their unique historical and social contexts, which have to be taken into consideration during research. The qualitative tradition recognizes the subjective individual creating of meaning, Denzin and Lincoln (2011) theorize that social reality is subjective, while Hesse-Biber, Rodriguez and Frost, (2015) add that the meanings and narratives are constructed by the individuals within their special social contexts. Thus, qualitative methods give more than just a snapshot of a question in the views of Miles and Huberman (2009), but also reflects on the mechanisms underlying social phenomena. According to Erickson (1977) social meaning lays in the actions of the participants, or in the context of this project their oral and written artifacts, online data corpora (Miles and Huberman, 2009). The vast interpretative contribution of the researcher in understanding of the concepts is also the own of such methods (Hennink, Hutter and Bailey, 2011), contributing to the overall understanding of mechanisms, motives, arguments, emotions etc.

Naturally, all types of research methods have both their advantages as well as their limitations, the same is true of the qualitative tradition (Ritchie et al., 2014). When designing the research project serving as the core of this thesis a myriad of methodological solutions were weighed for use. Due to the sensitive character of the topic of infertility and its treatments and the explorative nature of the research, it was decided that the issue is better examined using qualitative methods. One the one hand qualitative techniques allow the participants to relate to the questions freely and permits the researcher to receive a detailed view on experiences, perceptions and interpretations on the subject as well as positive and negative opinions. The possibility of analysing the unrestricted (naturally occurring) use of the language is also a key positive factor of qualitative methods, adding to the achieving of the 'Verstehen' level of understanding (Vicsek, 2006). On the other hand, qualitative interpretation of online discussions and traces, allows for the narrative details to emerge, and the inquiry is not limited to only testing an earlier set of hypotheses, it allows for the narrative map to cover a wider range of topics, emotions and underlying reasonings (Bauer, 2017c; Kozinets and Gambetti, 2021).

While achieving an in-depth ‘Verstehen’ for the particular analysed group (or corpora), the chosen qualitative methods indeed have some limitations. These are mainly connected to generalizability and that the methods do not yield representative results for the Hungarian population. The question of if findings are relevant outside the particular study or the study’s population is a key dilemma regarding qualitative research (Ritchie et al., 2014). Questions of reliability and validity can also be raised regarding the methods, these methods have its limitations regarding external validity (Ritchie et al., 2014). Some of the issues of generalizability of the online discussion analysis, the netnography coincide with the generalizability of focus groups (for example some topics may occur in one forum/group and not touched in another) (Vicsek, 2010; Kozinets, 2020).

When dealing with netnography, the data analysis of internet forums ethical considerations is also to be seriously taken into account (Lehner-Mear, 2019). One implication is the distinction between the private and public spheres, which on the internet is not as clear as on other venues (Eysenbach and Till, 2001). Kozinets has coined this dilemma “the consent gap in netnography” (Kozinets, 2020, p. 175). 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 if the identity of the subjects is 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? (According to methodological literature, the ethical implications may be even more pronounced in qualitative research than quantitative research because of the nature of the topics (Hennink, Hutter and Bailey, 2011)).

The ethical dilemmas were as such seriously taken into consideration. Before applying for ethical committee approval all aspects of Kozinets’s ethics process of netnography were considered¹⁹. The research design was approved by the competent ethics committee (Research Ethics Committee of the Faculty of Social Sciences and International Relations of the Budapest Corvinus University - where the research is based) on 4th of March 2014. Naturally all data collection and storage adhere with GDPR and Hungarian regulations. To assure full protection for online authors, their fantasy-names,

¹⁹ The detailed steps for this self-evaluation of netnographic research can be found in Kozinets (2020, p. 179) dubbed A research ethics process flowchart for netnography.

nicks have also been anonymized, and the original Hungarian texts are stored on a secure and password protected server.

While qualitative or semi-structured interviews pose less divisive moral dilemmas for the researcher, sensitive and intimate topics' interview participants and data must also be handled with special care. The interviews must happen in an environment that feels safe for the answerer, and the researcher must be ready to stop the interview process, whenever the situation seems stressful. Empathy over results is a prominent ethical guideline when conducting such conversations (Hirsch, 1999). A number of our interviewees where contemplating and explaining harsh, complex decisions they faced for the first time, preserving their feelings of confidence in the process, all the while offering emotional harbour was at times also taxing for the interviewers (amongst them the author of this dissertation).

7.2. Multimethod approach within the qualitative paradigm

Hunter and Brewer (2015, p. 187) determine multimethod research design as the following: “*Multimethod research may be broadly defined as the practice of employing two or more different methods or styles of research within the same study or research program rather than confining the research to the use of a single method*”. In addition, multimethods allow for a variety of questions to be investigated about a given phenomenon, all the while addressing a broad array of interpretations and criteria (Hunter and Brewer, 2015).

While uniting different methodological approaches is gaining more relevance in the last few decades in social scientific inquiry, there is often a methodological misunderstanding when defining multimethod and mixed-method research (Mik-Meyer, 2020). Even today, by and large when hearing the term multimethod research design the first instinct is to think of complementing quantitative methodology with a qualitative approach – which is actually the mixed-methods paradigm (Pekkanen and Pekkanen, 2020) –, instead of the correct definition, that entails the use of multiple forms of qualitative or quantitative data within their own paradigms (Creswell, 2015; Hesse-Biber, Rodriguez and Frost, 2015; Silverman, 2020).

Arguments are to be made for the benefit of combining diverse methods from the

qualitative research paradigm and emphasising on the value of the separate approaches within the same epistemological perspectives. This flexible dovetailing of methods can strengthen the quality of the research, it can “*allow for different angles and nuances to be visible...and provide knowledge that otherwise is inaccessible to the researcher*” (Mik-Meyer, 2020, pp. 7-8). Hunter and Brewer (2015) argue that applying multimethods design also is a helpful tool to overcome some weaknesses or limitations of individual methods (i.e., too narrow focus, generalizability (Hesse-Biber, Rodriguez and Frost, 2015)). One course to overcome these limitations of qualitatively driven multimethod projects call for a second (or third) qualitative method as an auxiliary element. This second (or third) method can serve a “*supplementary function*”, but its main focus is to support the core qualitative method (Hesse-Biber, Rodriguez and Frost, 2015). This type of reasoning is behind how the results of the three distinct, but complementary methods are presented in this doctoral dissertation²⁰.

Contrasting all the enumerated benefits of multimethod strategies Hine (2015) points to some challenges that need to be addressed: (1) the methods may bring contrasting results; (2) the examined phenomena may in fact be different; (3) the population examined may not be aligned (especially in the offline and online realms). All these factors were taken into consideration when planning the project, and the research team found the benefits outweighed the potential hindrances.

In current case complementing a netnography with in-depth interviews, using the latter method makes it possible augment the results with those dimensions that do not, or only scarcely appear in the web-sphere. One example of the advantages of this type of “co-analysis” is that unprompted online discussions rarely touch upon ethical dimensions regarding spare embryos, while when asked using the active interview technique valuable insights were unveiled about lay morality and complex ethical decision-making (Vicsek, Sándor and Bauer, 2021). The benefit of supplementing interview data with texts from online conversations streams is that some topics are so intimate, that face-to-face interviews are extremely hard to conduct and may also be stressful for the participants. The anonymity provided by the online realm helps alleviate such tensions and research participants may express themselves more freely, without constraint (Wallace, 2006;

²⁰ More detail on this practical decision is introduced earlier in the introduction of this chapter (Chapter 7).

Bauer, 2017c).

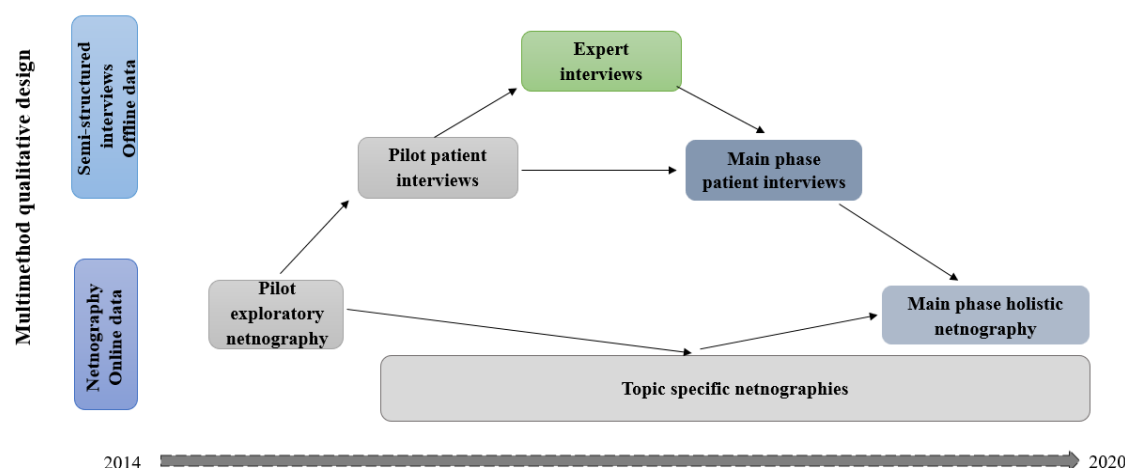
7.3. Research design, the multimethod framework of the thesis

Research design presented in the thesis is interpreted based on Hunter and Brewer (2015, p. 18) as “*the out-come of prescriptive planning ... where specification and selection of such elements as units of investigation, universes, sampling frames, sampling techniques, measurement, data transformation, and modes of analysis are thoughtfully defined in detail.*”. Hine (2015) posits that combining interpretation of online and offline data, and synthesizing its results is a unique intellectual challenge, yet an extremely fruitful part of Internet research. Moreover, multimethod design with concurrent online and offline methods intend to provide triangulation (Creswell, 2015) and offers a “luxurious abundance of data” (Hine, 2015, p. 504). The rest of the chapter is dedicated to introducing this online and offline synthesizing framework of the thesis.

As introduced above the methodology of the thesis employs a multimethods qualitative framework – relying primarily on netnographic analysis, complemented with patient and expert interviews. The methods follow an iterative design, with each stage / method influencing the next, clarifying and adding to the holistic picture. The main sources of data are the corpora of online conversations and traces, using the qualitative patient interviews for additional in-depth qualitative insights. The expert interviews are used to add context to the study.

The multimethod approach is twofold in the research of the thesis. On the one hand it combines the two very distinct methods of netnography and interviews, while on the other hand the analysis also combines large-scale and small-scale approaches to open-web research. According to Hine (2015) this way of thinking about online investigation has manifold advantages without redundancy: (1) gives additional explanatory power; (2) offers complementary and distinct ways for understanding; (3) adds depth and meaning; (4) underpins triangulation.

Along these lines, the below model shows the data collection of the various methods influenced each other, as well as the analytic directions and concrete execution of the thematic analysis.



6. Figure: The methodological design of the research

The first pilot exploratory netnography was limited to only two popular forum threads and served to provide an overview of topics and emotions in online conversations about infertility and medically assisted reproduction²¹ (Bauer, 2013). The forum analysis proved to provide fruitful insights for pilot patient interviews (Szolnoki, 2015; Vicsek and Szolnoki, 2015) and also laid the groundwork for subsequent topic specific and holistic netnographies conducted from 2015-2020 (Bauer, 2015, Bauer, 2016, Bauer, 2017a, 2017b). As the methodological framework model above shows the framework of holistic netnography was also influenced by the results of the main phase patient and the specific expert interviews. Both of these were partially conducted by the author of the dissertation and enriched the netnographic analysis with dimensions such as ethical dilemmas (Vicsek, Bauer and Szolnoki, 2019; Vicsek, Sándor and Bauer, 2021) and gave a glimpse into the physician's side of the evolving doctor patient relationship (Sándor, Vicsek and Bauer, 2017).

7.4. The applied methods detailed

The succeeding subchapters introduce the two research methods netnography and in-depth semi-structured interviews and their application in the research project, before

²¹ This exploration still adhered to a less holistic view on online trace data, which was later reconsidered by the author to include other relevant social media platforms in her subsequent projects.

familiarizing the reader with the concepts and steps of thematic analysis.

7.4.1. Netnography

7.4.1.1. Netnography defined

Netnography is a relatively new, complexly designed and ever evolving research method. Compared to traditional methods its methodological practices are less set in stone, as the data source for netnography is in constant flux (the evolution and unique qualities of the data corpora will be detailed in the following subchapter of the dissertation).

The term netnography was coined by Kozinets in 1995, and originally the method was used to investigate research questions in the fields of marketing and market research (Dörnyei and Mitev, 2010). While netnography is still a strong technique in these fields, the past decade has shown the research community that the method is also applicable for sociological inquiry, and recently more sociological studies have been conducted using netnography as main or complementary methodology (e.g., Elvey et al., 2018; Langer and Beckman, 2005; Pittman et al., 2017; Victoria Diniz et al., 2018).

Per definition, netnography is an organized set of research tools – a specific way to conduct online and social media research (Kozinets, 2015; 2020; 2021). Netnography is a form of qualitative research, a unique form of digital anthropology “*that seeks to understand the cultural experiences that encompass and are reflected within the traces, practices, networks and systems of social media...the three fundamental elements of netnography: investigation, interaction and immersion...*” (Kozinets, 2020, p. 14). The method is tied into other qualitative methodologies, it is linked to the practices and dispositions of sociology and anthropology.

Based on tenets of Kozinets netnography is (1) focused on the human experience and cultural understanding; (2) grounded deep in the context of everyday life; (3) aims to explore social systems of shared meaning; and is (4) driven by self-awareness of the researcher and the participants.

During a large or small-scale netnography the so-called online traces are investigated, which can be a myriad of online forms of expressions and interactions –

these identified traces can be in the forms of text, graphic, photographic, audio-visual, musical. The form of data, and the way they are collected (in the case of this thesis through keyword and filter-based algorithms) genuinely sets netnography apart from traditional ethnographic traditions, but the mindset of the netnographic researcher shows particular similarities to ethnographers in focus on granularity and deep interpretation rooted in the ideas of Geertz (empathic Verstehen). The analysis focuses on use of language, new language and symbols, interpretation of online rituals, assumed roles in the online realm, telling of stories, sharing of beliefs, articulated and reinforced values, and power relations and inter-group dynamics.

Kozinets was the first of scholars, who formalized the netnographic method and created a “*new discipline that adapted ethnographic and qualitative research methods to the novel and still emerging contingencies of social media environments.*” (Kozinets, 2020, p. 7). Since then, several different terms have arisen for describing the general category of applying ethnographic research methods to online environments and data, these adjacent terms are: ‘cyber-ethnography’, ‘virtual ethnography’, ‘network ethnography’, ‘webnography’ and ‘digital ethnography’. Though the terms vary, the method always stood for a type of cultural focus of understanding of the online data (Kozinets, 2010; 2020).

According to Rheingold (2000), Eysenbach et al. (2004) and Salmons (2015), online, virtual communities provide a significant human social experience, along with relevant emotional realities, and virtual self-identification, persona-building and group dynamics. Markham (1998) and Kozinets (2010, 2020) agree that online life can be interpreted as evolving cultural context – with the demarcation between body, self and computer becoming somewhat murky (Hine, 2015). Perren and Kozinets (2018) argue that online platforms and networks provide an opportunity for social interactions, achieving ‘consociality’ which refers to a co-presence, which has originally been defined as being physically present within the same time and space, modifying this definition to fit the online sphere. To clarify this, online community interactions to some extent mirror offline social dynamics (Ayers and Kronenfeld, 2007; Nettleton et al., 2005), but also provide important distinctions that need to become the focal points of analyses (Hine, 2015; Salmons, 2015).

7.4.1.2. The sources of data

Kozinets follows Nick Couldry's (2012) definition of media: 'institutionalized structures, forms, formats and interfaces for disseminating symbolic content' and remarks that in the 21st century '*virtually all symbolic content is digital...and many platforms carry both mass-produced content and interpersonal communication*' (Couldry, 2012 cited by Kozinets, 2020, p. 67).

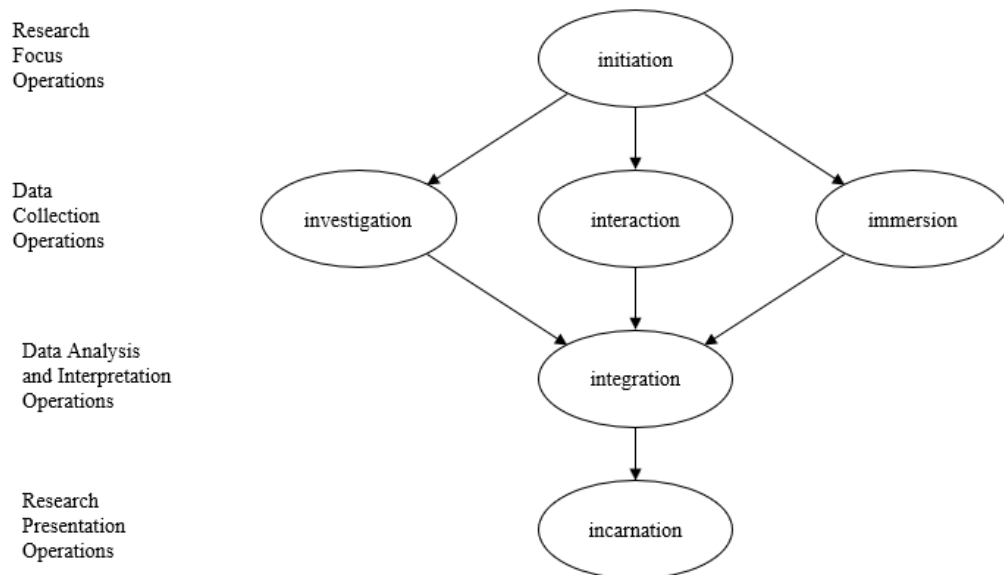
This definition can be further refined to consider the distinctions of social media. Ulrike Gretzel in 2017 had defined social media data as the following: „*Web-based communication platforms or applications that take advantage of Web 2.0. technologies, which make it possible for users without technical expertise to easily produce and publish content on the Internet, Social media encompass a variety of different types, such as social networks, review sites, instant messaging applications, and video and photo sharing sites.*” (Gretzel, 2017 cited by Kozinets, 2020, p. 4).

Adequately defining social media data is a challenging task, as it is constantly evolving, new platforms are created, old ones abandoned. In just the last decade the composition of the online communication sphere has shifted radically, social media has come to the forefront of the communication, and its rules and practices has significantly changed online discussions, debates and what topics or themes become and stay part of the online communication agenda.

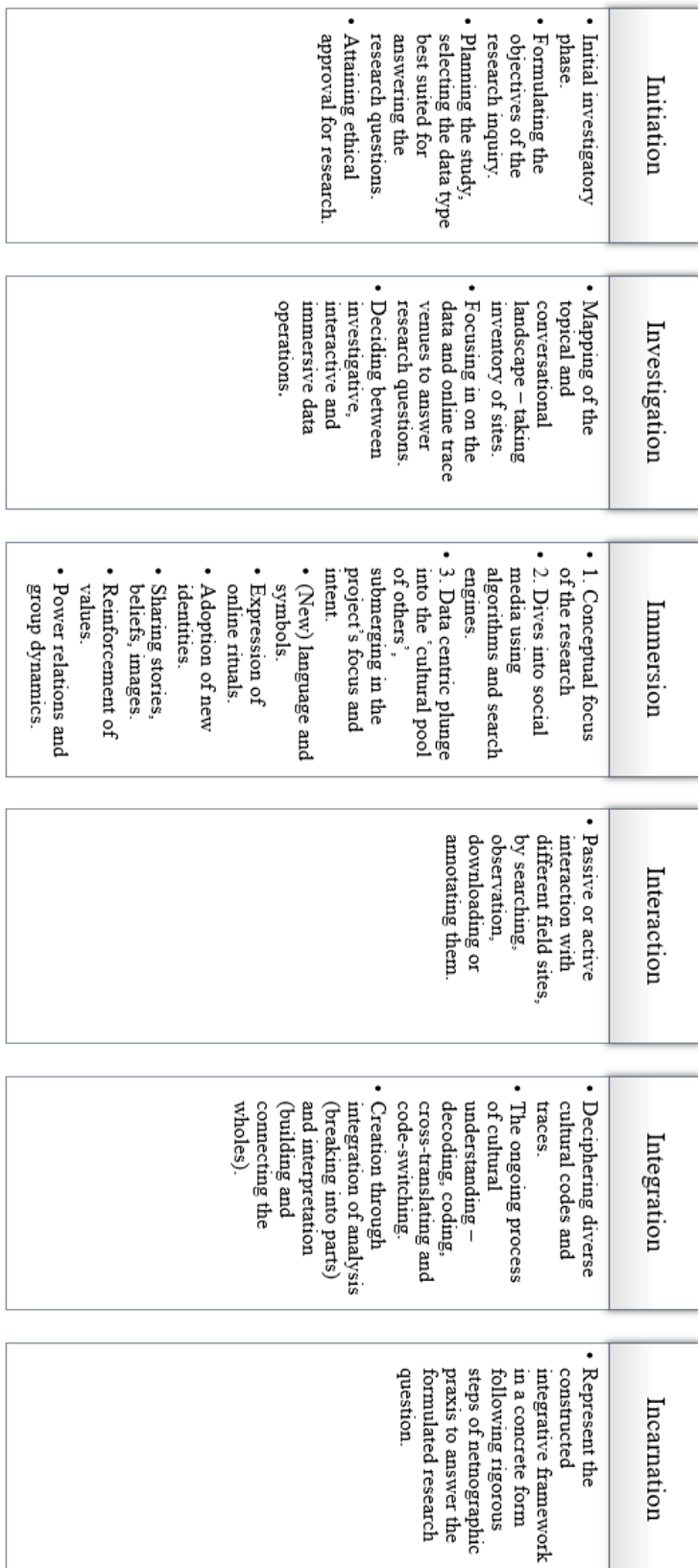
According to Kozinets (2020, p. 5): “*Social media today thus comprise of a complex social system that reflects and reveals human society and is also itself a unique social phenomenon. Netnography is designed to help you make sense of that system and the way people interact with and within it.*”. In line with the evolution of the online sphere, netnography's focus recently has shifted to the investigation of social media from other online platforms. In fact, Kozinets (2020, 2021) has determined systematic social media investigation as one of the major goals of the research method.

7.4.1.3. The operational steps of netnography

Netnography as other methodologies has its operational steps, what Kozinets (2020) has coined netnographic praxis, and he identified six procedural movements of netnographic inquiry, the six 'I'-s: (1) initiation, (2) investigation, (3) immersion, (4) interaction, (5) integration, and (6) incarnation. The below figures show the conceptual details and the order of application of these operational steps of netnography, and subsequently introduce how this framework of Kozinets was carried out in the thesis field research. The techniques of netnography are constantly updated to maintain a handle on the everchanging data, as the forms of online traces and interactions are in constant flux. The characteristics of the online traces and the evolution of the data stream is discussed next.



7. Figure: The six procedural movements of netnography, research timeline based on Kozintes, 2020, p. 139.



8. Figure: The six procedural movements of netnography explained (Kozinets, 2020)

Initiation	<ul style="list-style-type: none"> • Choosing the main concepts and definitions for the research – a more encompassing approach, including MAR technologies not just ART (detailed in Chapter 2). • Opting for a holistic approach to online data and interactive data collection (detailed in Chapter 7.4.1.2) • Attaining ethical approval for research through the encompassing OTKA project.
Investigation	<ul style="list-style-type: none"> • Mapping of the topical and conversational landscape – taking inventory of sites. Finding the relevant infertility forums, acquainting with the sites of fertility clinics. Looking into discussion groups with related women's health issues. • Deciding on the patient contributed content for small scale netnography in Chapter 7.4.1.2. • The thesis research decided on combining immersion, interaction and integration but kept the netnography strictly a passive observation.
Immersion	<ul style="list-style-type: none"> • 1. Patient narratives became the focus. • 2. Online trace data was extracted via a social media monitoring software, using several different string of keywords. • 3. To understand the online traces, the research immersed herself in the portrayed. • Expression of online rituals. Chapter 8.1.1. & 8.1.2. • Power relations and group dynamics. Chapter 8.1.3 • (New) language and symbols (softening words and emojis) – Chapter 8.1.4. • Adoption of new identities. Chapter 8.2. • Sharing stories, beliefs, images. Chapter 8.2. • Reinforcement of values. Chapter 8.2.
Interaction	<ul style="list-style-type: none"> • Passive interaction with field sites, by searching, observation, downloading or annotating them in the data collection software and field notes. • Active interaction was avoided throughout the netnographies, but the relevant online discussion groups were used as a venue of patient interview recruitment by the author of this thesis by posting a call for research participation (Chapter 7.4.2).
Integration	<ul style="list-style-type: none"> • An online conversation map was drawn based on the main themes identified and qualitatively coded in the texts. • The thirteen main thematic hubs were quite diverse (Chapter 8.2) and some in line with the theoretical frameworks were investigated at greater length. • Lay expertise in Chapter 8.3. • Doctor-patient relationship and interaction in Chapter 8.4. • Gendered genetic responsibility in Chapter 8.4. • The online and offline data were connected by searching for similarities and contrasts.
Incarnation	<ul style="list-style-type: none"> • The finding of the netnographic field work is the main prong of the results of this dissertation. • Parallel to work on the thesis the author has presented the preliminary or thematic results at multiple conferences and publications detailed in on the last pages of the dissertation's Appendix.

9. Figure: Kozinets's (2020) six procedural movements of netnography adapted to thesis research

7.4.1.4. Netnographic methodological decisions of the thesis research

The above figure shows how the framework of Kozintes was adopted for the particularities of the thesis research. Below the methodological and data choices are explained in detail and the research specifics are introduced.

The sources of thesis data

Acknowledging Kozinets's notion, that understanding the complicated mechanisms of social media is imperative, my reasoning is that shifting focus solely on social media, limits research and especially sets unnecessary boundaries for sociological inquiry. Thus, during the data collection for this 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.

Reasoning behind this decision is manifold: (1) with not restricting the sources of data a larger corpora can be examined; (2) the function of the different platforms is divergent, thus the collected multimodal data can yield richer, more comprehensive results; (3) the different types of investigated traces allow for comparisons to be made; (4) the intimate topic of infertility and its medical treatment triggers diverse online interactions – with peculiarities linked to specific online platforms – and the inclusive dataset allows a glance into these dissimilarities; (5) the intimate, but publicly accessible, patient-to-patient communication foremost appears on non-social media based open-web sources such as blogs, or forum discussion threads (Bauer, 2017c), but (6) public attitudes towards biomedical technologies are foremost expressed in Facebook comments (Bauer, 2021a, 2021b).

Consequently, taking the above arguments into consideration, the assembly of online traces for my research takes a broader approach to online data, which also includes those sources that are not part of the above defined traditional social media generated data, but that also comprises of online internet forums, discussion groups and edited content such as blogs, and their comment sections along with those of edited news portals. This mapping of the relevant online space invokes the practices of early netnographic studies (Kozintes, 2020), and I have found that it is beneficial in grounding wide-spectrum exploratory research projects such as the one serving as the base of the dissertation.

Thus, the online, netnographic part of my research is a multimethod combination of large-scale and small-scale approaches to open web research. The dissertation moulds findings from these two branches of online data in order to investigate a larger spectrum and offer a holistic overview of virtual communities and their communication, narrowing in on thematic focal points, distinguishing narratives internal and external perspectives and interaction styles.

Practically speaking, in the first ‘large-scale’ prong of the project I analysed the whole dataset and looked at the main trends and topics, investigating the relevant trends and dynamics of infertility and its treatment online discourses²². Then in the second ‘small-scale’ stage of the netnographic analysis I filtered from the large dataset the patient conversations and performed an in-depth qualitative thematic analysis on the posts and comments on a sample of published traces from these conversation threads. The results of the latter are published in the dissertation concentrating on emergent overarching themes, and less on the temporal dynamics and trends²³. The reporting of the thesis aims to draw a narrative map of the main topics and themes of conversation amongst women participating in these online discussion communities.

The data for the netnographic explorations was isolated and collected using social media monitoring software Talkwalker^{24, 25}. The online tool gathers open web data based on search algorithms, keyword-based syntaxes, language, and geolocation filters – these were the criteria for large-scale sampling²⁶. The software has the capacity to reach and store historical data. This holistic keyword-based data isolation gave the corpus of the large-scale data, and subsequently provided the foundations for the small-scale sampling.

²² The thesis label ‘discourse’ for the corpus of online traces, following a more lax definition adopted in netnographic studies. While the research acknowledges the immense literature behind discourse analysis and its extensive theoretical and analytical debates, the dissertation does dive deep into them. A systemic review of DA of social media data is introduced in Tamássy and Géring (2021).

²³ A comparative analysis of a large scale netnography and the small scale one introduced in the thesis is a manuscript of the author, planned to be submitted for review early 2022.

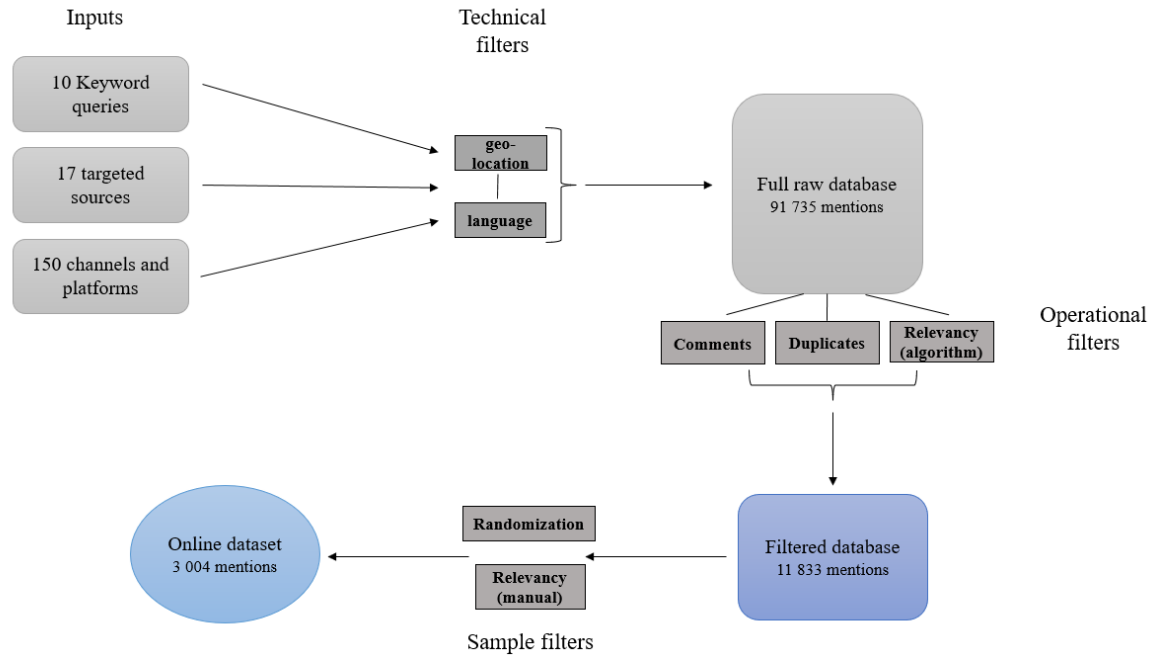
²⁴ The international software adheres to the GDPR regulations, national legal frameworks and the data policy of the social media channels and open web domains. The user generated content and interactions are anonymized within the software and only the edited content creators (journalists, public bloggers, official sites of public personas – i.e., politicians, thought leaders etc.)

²⁵ Access to the software and the dataset was granted by Ynsight Research, the place of employment of the author of the dissertation.

²⁶ The detailed keyword-syntaxes can be found in the Appendix portion of the thesis.

Details of the data collection and sampling

The below figure illustrates the methodological decisions made while collecting the online dataset.



10. Figure. The process of online data collection

The data collection procedure is preceded by an exploratory online research phase²⁷ 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 conversation²⁸. Keywords, 17 targeted sources²⁹ and 150 channels and platforms³⁰

²⁷ During this preliminary online exploration, the author of the thesis acquainted herself with the online topics and sites in connection to medically assisted reproduction. During this period of exploratory reading and note-taking she examined over 10 000 online mentions, going back as far as 2006. Many of these mentions were not added to the final online dataset because they were outside of the set timeframe.

²⁸ The results of this exploratory keyword search have served as the base for reporting on online language use in Chapter 8.1.4. of the dissertation.

²⁹ The 17 targeted sources met the following criteria: (1) the discussion groups and threads were chosen based on popularity and reach, so those domains that are ranked at with the highest popularity; (2) beside frequency measures sites that deal with the broadest topics were be selected (based on interpretations of the discussion titles and explorative methodological reading); and (3) the thread had to be open-web data source, and fit the criteria of being accessible and readable for the public without registration.

³⁰ The encompassing approach to online data and its methodological implications are detailed in Chapter 7.4.1.2. of the dissertation.

were compiled into a ‘topic query’ using Boolean operators. To create the final syntax technical filters – pinpointing data sources by 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 algorithmic relevance filter also excluded comments that were only comprised of 1 word or emoji. While including these types of comments may make sense in a large-scale netnography, or a quantitative online text-analysis, the thesis research was looking for comments and posts that can be analysed from an in-depth qualitative approach.

Sampling operations for the final dataset: 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 detailed below and consisted of 3004 relevant, non-duplicate, unique online comments and posts coming from 232 unique sites.

7.4.2. In-depth, qualitative interviews

A series of qualitative research interviews were conducted throughout the comprehensive OTKA funded research project (K108981). As introduced earlier in this dissertation these qualitative interviews are used as a complementary methodology to the netnographic inquiry in the multimethod research project.³¹

Adapting the definitional elements of Kvale (1983), the purpose of qualitative interviews is not to acquire quantifiable data, but rather get broad insights that allows the researcher a glimpse into the life-world of the participant, striving to understand the views and perspectives of the interviewee. Similar are the dispositions of King (1994) or King, Horrocks and Brooks (2019). Semi-structured interviews (or as King (1994) and Mason (2002, 2018) refer to them as qualitative interviews, as do I in the dissertation) allow the researcher to access data that is mainly relevant to the research question yet allows the participant to express and form opinions and understandings through the series of open-ended questions.

An initial structure is needed, but the topic at hand, most likely require a great deal of flexibility and empathy towards the participants of the research with a level of interaction and dialogue (Mason, 2002). In the words of Burgess (1984) they shall be ‘conversations with a purpose’ (Burgess cited by Mason, 2002, p. 62). The openness of the questions allows the subjects to express desires, beliefs, emotions, and opinions quite freely, giving the participant the more significant role. This type of expressive freedom, and feelings of maintained control can help interviewees relax into an otherwise emotional and potentially stressful conversation. Talking about biographical disruptions, such as conception failure and the physically and emotionally taxing medical procedures are imminently difficult even if the interviewer does all to alleviate these tensions. Those patient interviews were the longest (some were over two and a half hours), and the most impassioned and stirring where the participant was either in the midst of an IVF cycle, or many procedures have failed already, and the patient was losing hope.

The participants of the eighteen patient interviews were all women, who had or

³¹ Relevant results from the findings based on the interviews were published by Vicsek and research team (Vicsek and Szolnoki, 2015; Szolnoki, 2015; Sándor, Vicsek and Bauer, 2017; Vicsek, Bauer and Szolnoki, 2019; Vicsek, Sándor and Bauer, 2021).

were involved in ongoing assisted reproduction cycles³². One of the limitations of the research is exactly this, that men proved to be an unreachable population for us. In this sense this thesis adds to the plethora of knowledge from women's perspective as men proved unreachable both through interviews and the focused small-scale netnography. While this is a general challenge for qualitative research dealing with issues of fertility, infertility, and assisted reproduction (Reed (2012) also reported a self-selective sampling bias in her research on genetic responsibility and screenings, similar challenges were reported by Szalma's qualitative endeavours (2021a, 2021b)), future research in the topic should aim to overcome this gap.

Rapp (2000) also points to this specific methodological problem with research sampling for reproduction topic research. Men are a much harder to reach population – especially when investigating infertility. This unfortunate fact is grounded in several mechanisms: (1) men are less willing to discuss medical issues; (2) men are much more seekers of information on medical issues, then actively discussing them (3) men are still facing more stigmatization than compassion when it comes to infertility (4) embarrassed to talk about problems (5) still a segment of society that sees women responsible for problems with conceiving (6) thus men are much less prone to go and get checked out³³.

During the planning of the interview stain of the research project, our team considered to attempt couples-interviews, hoping that female partners can influence their male counterparts to participate. While theoretically this seemed to be a solid concept, our initial experiences and other researchers' encounters discouraged us from taking this methodological road. Hirsch (1999) had concluded that couples interviews place unwanted burden on the couples' relationship in an already stressful life-course and argued that this potential harm goes against the ethics of the qualitative research paradigm.

Taking all this into account we can make the following remarks about the sampling strategy for the in-depth patient interviews. Qualitative sampling is not random (using non-probability samples), it is purposive selecting subjects based on certain prescribed criteria of the research, the members of the sample must represent the salient

³² The details of the interview participants are summarized in Figure:11 of this dissertation chapter.

³³ Unequal gendered reproductive responsibility and attitudes are detailed in Chapter 3.4. of the dissertation.

characteristics defined by the researcher. The sample is not set to be representative of the whole larger population, although some traits of the sub-population can be registered due to making the sample as diverse as the defined population allows it to be (Ritchie et al., 2014; Silverman, 2020).

Due to the manner and topic of the research the snowball method was used to find the participants for the research. Snowball sampling or in other words chain referral sampling is quite popular technique when considering qualitative research methods, especially when the population is hard to reach, or the subject is rather sensitive and private, where the subjects themselves suggest further subjects they know based on the required characteristics (Biernacki and Waldorf, 1981). One of the main advantages of the snowball sampling strategy is that it allows the researcher to reach hidden populations quite easily, those populations that are unlocatable with other methods (Atkinson and Flint, 2001). Other positive feature is the trust that is implied through the referral in case of sensitive subjects such as the topic of this research.

Thus, our approach to the sampling was twofold, starting the referral chain was based on two approaches: (1) personal acquaintance of interviewer and through her access to the members of a ‘treatment support group’; (2) an invitation for research participation was published on all relevant discussion threads and public groups. The recruitment proved rather difficult, as many participants who agreed to an interview either got cold feet or asked for the interview to be terminated. After months of organizing and reorganizing the interviews the below sample was achieved. Both the beneficial and the limiting characteristics of snowball sampling is apparent in our final sample of eighteen women. We can see that while they are less heterogenous when considering their demographic and educational constitution, other characteristics make the sample beneficial for research.

Educational level		
College/university degree or in progress: 14	Completed secondary education: 3	Vocational education: 1
Partnership status		
Married: 14	Stable relationship: 3	Singles: 1
Religion		
Non-religious: 3	Spiritual, but do not attend church: 7	Religious and follows the teachings of the church: 7
Age groups		
Under 35: 6	35-40: 7	Above 40: 5
Number of treatment cycles		
0-2: 12	3-4: 4	5+: 2
Number of clinics visited		
1 clinic: 10	2 clinics: 6	3 or more clinics: 2
Number of children		
No children: 11 (2 currently pregnant)	1 child: 4	2 or more children: 3

11. Figure: Summary information on the composition of the participants of the qualitative patient interviews

We can observe that several of the participants have had multiple treatment cycles at different clinics. As it will be introduced in greater detail in subsequent analysis chapter the position occupied in the treatment pathway has significant influence on the patients' narratives and dispositions towards technology, treatment, and medical professionals, especially if these treatment cycles have not been successful and they do not have children.

The guide for the interviews adopted the funnel approach, opening with a general account from the patient (emphasizing background, experiences, and emotion) and then focusing in on specific subtopic about embryos and morally challenging decision making. The thesis focuses foremost on the broader themes touched upon, while the details of the ethical decisions concerning embryos can be read in Vicsek, Bauer and Szolnoki (2019) and Vicsek, Sándor and Bauer (2021).

All patients provided a consent form after being acquainted with the background and objectives of the research. Their contribution was not paid for, but, when possible, drinks and snacks were provided. The interviews took place between 2015-2016 (the author of this thesis was part of the team organizing and leading the discussions) and lasted from one to over three hours. To accommodate the patients as much as possible some took place in locations suggested by them (either very private or venues they felt comfortable to talk for a long time), or via Skype or Viber calls for those women who wished for extra privacy. While the researchers did everything to create a safe and compassionate environment a handful of the interviews were heavily emotional. All the interviews were transcribed, the transcripts then analysed with the help of NVivo and MAXQDA software. For the thesis research the themes examined are in line with the main points of the research questions.

7.4.3. Expert interviews

The expert interviews serve the purpose of offering background information and context to the research. This function was especially pertinent during the investigation of the third research question (RQ3) dealing with the online and offline representations of the doctor-patient relationship. While the expert interviews will not be analysed in full detail (a practical choice that was explained in Chapter 7.3. of the dissertation) they will be referenced when they provide valuable context to patient narratives, or when their exhibited opinions or values are significantly different to those of the patients.³⁴

In our OTKA study twelve semi-structured interviews were conducted with infertility treatment professionals within the research. A diverse sample was aimed for: the sample is heterogeneous with respect to occupation, clinic type, age, and gender, details depicted in the Figure below. The reasoning for this heterogeneous sample of experts was manifold. Firstly, as we could see earlier in the theoretical section of the dissertation (Chapter 3.4) attitudes towards childbearing, infertility and medically assisted reproduction has a gendered aspect. Secondly, the above is also influenced heavily by age. Thirdly, the occupation of the experts directly influences the nature and situational or temporal context of their interactions with the patients.

³⁴ A full analysis of the expert interviews were published in Sándor, Vicsek and Bauer, 2017.

It is important to note here, that in the patients' accounts of interactions with the health care professionals they overwhelmingly referenced experiences with their gynaecologists (and to lesser extent nurses), while embryologist or laboratory professionals came up only in connection with procedure and embryos. The work of the first two groups were evaluated, while the other professionals appeared in neutral context both in the online and the offline patient data.

Initials of Name	Sex	Age group	Occupation ²
1. A.A.	female	40–59	lab assistant
2. Dr. K.I.	male	60–	gynecologist
3. D.A.	female	40–59	lab assistant
4. Dr. E.A.	female	25–39	gynecologist
5. G.B.	female	25–39	lab assistant
6. L.R.	male	40–59	embryologist
7. M.K.	male	40–59	embryologist
8. M.U.	female	25–39	Nurse
9. N.D.	female	60–	Nurse
10. Q.J.	female	60–	embryologist
11. R.A.	female	40–59	embryologist
12. Dr. R.F.	male	40–59	gynecologist

12. Figure: Participants of the expert interviews

Recruiting experts for the interviews was achieved by contacting several clinics and through independent expert consultants. The interviews took place either via Skype or at the clinic and were conducted by the author of this thesis and her tutor and research project lead, Lilla Vicsek. Due to the tight schedule of the experts the interviews were to the point, but not rushed, lasting between 30-60 minutes (significantly shorter and more structured than the in-depth qualitative patient interviews). Most experts received gifts for their contributions. All participants provided written informed consent, and initials were changed to provide anonymity (along with not disclosing the institutions where the interview participants were recruited).

7.5. Methods of analysis

7.5.1. Approaches to thematic analysis

The chosen method of qualitative analysis was thematic analysis, with the intent to structure the narrative chaos appearing in the online and offline datasets into patterns and themes that represent the most relevant and interesting aspects of the thesis research data (Boyatzis, 1998; Vaismoradi, Turunen and Bondas, 2013; Nowell et al., 2017). Based on Guest, MacQueen and Namey (2007) thematic analysis can be both exploratory and confirmatory based on the research approach applied to qualitative data. As such the reasoning can either be content-driven and inductive, or hypothesis-driven and deductive based on the exploratory or explanatory nature of the research. On the following pages I will as I will guide the reader through the process of the thematic analysis of the thesis research, I will parallel argue that these distinctions are less apparent in practice and sometimes the strict conceptual demarcations become blurred in the process.

Both the online data corpus and the transcripts of the interviews were the subject with rigorous qualitative thematic analysis guided by the six-step framework and guidelines presented by Braun and Clarke in their influential 2006 methodological paper. According to Braun and Clarke (2006, p. 10): *“A theme captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set”*. Similar was emphasized by Leininger (1985, p. 60) quoted by Aronson (1994) defines the formulating of themes as follows: *“bringing together components or fragments of ideas or experiences, which often are meaningless when viewed alone”*.

The approach of thematic analysis on the two datasets compiled by the two methodologies although are similar in practice, a few points of distinctions need to be highlighted, which stem from (1) the data itself; (2) the way the different datasets contribute to the multimethod methodological design of the thesis research.

The difference in the data is not only in its online vs. offline origin, or its length, but based on Bernard and Ryan (1998) two other dimensions had to be taken into consideration when the thematic analysis was conducted on the diverging datasets, even

though both are considered in present framework as text data. But while Bernard and Ryan (1998) make a clear distinction between 'text as a proxy for experience' and 'text as the object of analysis' I argue that in the case of the online conversation corpus the definitional line is blurred, and online trace data possess both of the argued dimensions of textual qualitative data. Because of the transgression between the data-type categories, the analysis of the of the online trace data dives deep into thematic analysis adopting tenets of grounded theory and draws a conversational and emotional map, but also pays close attention to the performance of group dynamics and linguistic expressions. The thematic analysis of the transcripts of both the patient in-depth interviews and the expert interviews are more in line with pure thematic experience, where the texts serve as proxies for different experiences of the doctor-patient dyad.

The thematic analysis is guided by two qualitative inquiry traditions. Firstly, analysis is guided by adapted principles of grounded theory (Charmaz, 2014; Corbin and Strauss, 2015), building on the contents of both the large-scale and small-scale online dataset. Secondly, some of the explored themes are inspired by the theoretical and empirical literature introduced in earlier chapters of the thesis (Fereday and Muir-Cochrane, 2006; Saldaña, 2009). Thus, throughout the framework creation and qualitative coding I resorted to both inductive and deductive reasoning.

Following the guidelines set up by Braun and Clarke (2006), the following phases were performed during the rigorous thematic analysis. (1) Familiarization with data; (2) generating initial codes; (3) searching for themes; (4) reviewing themes; (5) defining and naming themes; (6) producing the report.

7.5.2. Considerations and decisions for thematic analysis in the thesis research

This section of the chapter introduces the steps of the thematic analysis applied during the thesis research. Parallel to acquainting the reader with the six-step guideline of Braun and Clarke (2006, p. 88), its adaptation to the analysis of the thesis research is put forward.

(1) *Familiarizing yourself with your data*: this phase consists firstly, of data transcription in the case of interviews, and the for the online data, the exploratory keyword research and the manual relevancy filtering of isolated online comments

and posts³⁵. Secondly both datasets are re-read and initial ideas for analysis are noted, journaled. This immersion in the patient narratives and opinions gives a holistic overview of the online and offline datasets.

(2) *Generating initial codes*: Braun and Clarke (2006) posit that codes are meant to identify semantic or latent features in the data that are interesting for the project. In this phase we start to organize the data into meaningful groups. One main consideration that must be decided during the beginning of this process, which is what type of codes should be applied. Three possibilities have been identified: (1) content driven inductive categorization; (2) research question or hypothesis-driven deductive reasoning; or (3) a combined approach utilizing the benefits of both prior.

During the pilot phase of the netnography only inductive codes were created, with 4 main codes, and further 10 subcategories created. After this initial analysis, the thematic frame was revisited for the main phase of the netnography. One of the subcategories dealing with legal concerns was omitted, while 9 further codes and 15 subcategories were added. These added codes were decided upon with a combination of inductive and deductive reasoning. Latter based on theoretical and empirical literature related to research questions of the dissertation (RQ2; RQ3 and RQ4), augmented with findings from the pilot interviews.

The initial codes applied to the interview transcripts also followed dual reasoning, relying on the materials, but also the literature and the findings of the pilot phase netnography.

(3) *Searching for themes*: gathering and assigning all data to relevant themes, understanding the patterns in the dataset. This phase was an iterative process regarding both the online and offline data. The thirteen themes identified for the mapping of the online conversation were adapted to the relevant parts of the interview transcripts.

(4) *Reviewing themes*: The thirteen themes introduced to the online dataset were not revised, as those codes that did not work well were omitted after the pilot phase. Theme introduction was part of the interview analysis, the originally

³⁵ These methodological steps are introduced in Chapter 7.4.1.4. of the dissertation.

organized themes were augmented by themes relevant to the project's investigation of lay morality, ethically grounded decision making, and status construction of embryos (this decision was made using literature and specific research question oriented deductive reasoning).

(5) *Defining and naming themes*: the introduction and essence of each theme for the netnography can be explored in the dissertation, in Chapter 8.2. and its subchapters. The additional themes of the patient interviews are detailed in several publications of the author.³⁶

(6) *Producing the report*: this concluding phase of the thematic analysis entails bringing together compelling extracts, intertwining the data, the analytical findings, and the theoretical foundations of the project. One of the outputs of this analytical phase is the dissertation, while a comprehensive list of other works related to the research project can be found in the Related publications section of the thesis.

³⁶ Vicsek, Bauer and Szolnoki (2019) and Vicsek, Sándor and Bauer (2021).

8 Results and analysis

This section of the dissertation will introduce the findings of the thesis research, with the aim to answer the research questions while connecting the results to already existing theoretical and empirical results in the sociological field. At the end of each main section, I propose implications for further research to further the understanding of the topic of medically assisted reproduction. As detailed in the prior Data and methods chapter while the thesis research is multimethod designed due to the limitations in length for a doctoral dissertation the results of the netnographic pillar will be discussed in greater detail, while the two types of interviews will serve more as reference points in connecting the online and offline data (and the passive and active data gathering methods), focusing on supporting or contrasting findings.

8.1. The narrated experiences of patients

This section of the thesis will introduce the findings of the performed small scale netnography, mainly the results from the thematic analysis of the online traces published by the members participating in online communities discussing infertility and medically assisted reproduction³⁷. The aim of this chapter is to answer the first posed research question: *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. It aims to unveil what are the focus points and discussion topics salient to the online participants. By the thematical analysis of these messages the emotional drivers will be explored, along with the most important semiotic expressions. The section also augments the online narratives with those identified in the offline qualitative interviews to explore how the two different methodological approaches compare.

As such, the upcoming part first will give an overview of the conversation guided

³⁷ The Results and analysis portion of the dissertation relies on a re-interpretation and heavy expansion of the author's earlier publications (Bauer, 2013; Bauer, 2014a) and findings introduced during conference talks (Bauer, 2014b; 2014c; Bauer, 2015; 2017a; 2017d).

by the revealed typical patient pathways, as after the exploratory, meticulous reading and immersion in the texts these pathways were found to be overarchingly framing and guiding the online conversations. After the treatment pathways are explored, the next pages are devoted to the displayed emotions, emotional reflections seen in online community dynamics, and a semiotic analysis their online expressions (multi-model forms of online traces are examined) – the assembled patient dictionary, and an emoji-map will be presented and detailed.

These first parts lay the ground for the thematic analysis of the conversation. The thematic analysis endeavour begins first by the unveiling of a narrative map, followed by the introduction and evaluation of the identified themes. Three of the thirteen identified themes will be discussed in greater detail, diving into them more, to be able to provide answers to the posed research questions.

The guidelines followed for the thematic analysis in the thesis research along with the conceptual approach and interpretation of the online and offline qualitative data can be found in Chapter 7.5. of the dissertation.

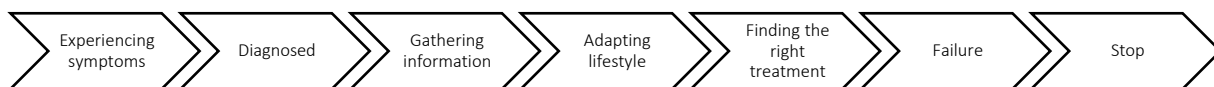
8.1.1. Typical patient pathways

Display and evolution of patient conversations can be viewed and structured based on descriptions of the treatment processes. The individual accounts can be modelled in distinct, yet typical infertility treatment patient pathways. Earlier it was shown that diagnosing and treating infertility has extremely rigorous and exact medical protocols (MHCH, 2019), while medical professionals at the infertility clinics abide by these, infertility being such a complex medical phenomenon, there are some specificities to individual treatment procedures and treatment cycles. The granularity of the medical decisions and weighing of diverse aspects are detailed in the work of Sándor, Vicsek and Bauer (2017), basing findings on the expert interviews.

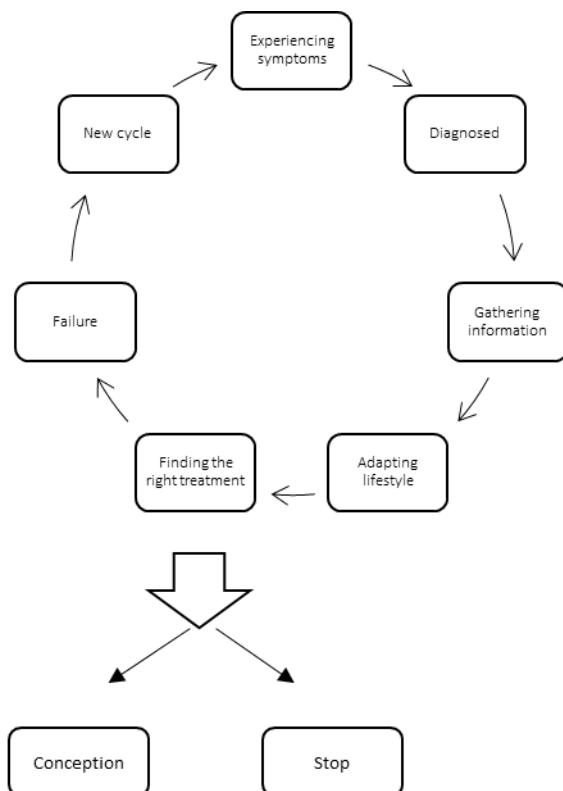
Based on the analysed online traces four main types of patient pathways could be identified and categorized, where the outcome was the main definitive point in how these pathways emerged and evolved. The four models are the following: (1) linear successful; (2) linear unsuccessful; (3) cyclical successful; (4) cyclical unsuccessful. The four case-types are illustrated below.



13. Figure: Linear successful patient pathway



14. Figure: Linear unsuccessful patient pathway



15. Figure: Cyclical patient pathways (successful and unsuccessful)

Linear successes are the most positive of possible scenarios, while cyclical unsuccessful show the greatest despair. During the latter the couple goes through multiple treatment types and multiple cycles without the positive outcome of conception. As the psychosocial empirical literature shows these are the most significant of biographical disruptions, often leading to severe depression, anxiety, feelings of grief and separation of participating couples (Holter et al., 2006; Mata, Boga and Bakonyi, 2001). The following verbatim illustrates how unsuccessful cycles trigger fear, hopelessness from patients:

'I think I am still wallowing in my rubbles, but I am not a hopeless case (at least I think). It looks like we made a decision and take on this month and try again. I AM SCARED and I feel that this is already a bad problem.' [online trace C173]³⁸

Despite the hardships we see that the majority patients continue on, try and try again, some with increasing stress, while some try to keep hanging on to hope as the cycles and failures reoccur, this paradox of strength in times of failure is commonly reported amongst patients with cyclical treatment paths, as with the author of the following comment:

'I have 4 insems and 4 testtubes behind me...BUT what I do know is that I was stronger with all of them and that I wanted it! When I got my period after the first insemin I cried. After the first tube I for went off the rails, balled my eyes out for weeks. But as time went by I became more and more strong and not exhausted or broken and sad, and went forward with strength of an ox' [online trace C5]

These types of patient reports can also be viewed in connection with the warrior narrative identified in the 'meaning of childlessness and infertility' theme introduced later in Chapter 8.2.2.5. of the dissertation.

Online discussions proved to play a key role in all stages of the pathway, providing the participants with support and information throughout the processes. Experiencing symptoms in the case of infertility treatment is problems with conceiving, and the conversations touch upon the initial shock and feelings of inadequacy. Women question their self-worth, at first search for everyday practices to enhance the odds of getting pregnant, while waiting for the second stage of the path, getting the proper diagnosis. As

³⁸ The original language of the texts is Hungarian, the quotations were translated by the author. To assure anonymity the nicks and the quoted nicks, or other names have been deleted from the quotes. Moreover, not adding the exact Hungarian verbatim to the text of the dissertation has both practical (length related) and ethical considerations. The latter relates to even greater anonymity protection not making the direct participant sentences searchable. The topic is discussed with granular detail in Henderson, Johnson and Auld (2013).

it will be discussed in the subsequent thematic chapters obtaining the proper diagnosis and starting the medically assisted reproduction treatment process has many hurdles, from experiences in the Hungarian health care system, through material burdens, to lack of support from social and familial relationships.

Information gathering, experiential knowledge and patients becoming the archetypes for ‘lay experts’ are at the core interest of this thesis.

‘some doctors know nothing about resistance, they say it causes miscarriages...in the beginning I tore my hair out because of this...but it should encourage you that your results don’t seem that bad, since there are studies that say they are good. If I were in your shoes I would not start taking the medication, but would start to follow the IR-PCOS diet instead...but it is your decision, you are the one who knows’ [online trace C38]

Lack of information is one the major stressor factors for patients, and when the official sources fail to address this need, the participating women turn to the online sphere, and find valuable knowledge in their online peer discussions, as observable in the comment below and detailed in greater depth in the chapter discussing the findings related to the second research question (RQ2), Chapter 8.3..

‘I got the idea from the forum, that I should go to an endocrinologist and guess what my morning insulin is already extremely high....since then I started treatment I got my period almost normally.’ [online trace F19]

As a major biographical disruption (Bury, 1982; Engman, 2019) infertility treatment requires an abundance of time and energy. Unlike with many other procedures, patients need to alter their previous routines significantly, which can cause a great deal of stress to them. While adapting lifestyle may seem to be a difficulty the conversations show that there is little that the women partaking in these treatments would not do to succeed and have a baby. The interviews support this notion completely as findings of Vicsek and Szolnoki (2015) and Vicsek, Bauer and Szolnoki (2019) argue, the main goal is to become pregnant, and the hardships and the emotional and physical tolls take a backseat to achieving this life-changing ambition. Feelings of motherhood are explored in Chapter 8.2.3., but the following patient report sums up the yearning, the inadequacy and coping with disappointment complexly:

‘I think all women would take the hurdles on in this same way, because there is no other option. This is the way. Yearning for a baby overrides everything. If it does not happen for the twentieth time, you have to get up for the twenty-first. What other choice do you have? Stopping and living without a family? Accepting this is what you need emotional strength for I think. (btw this morning’s test was negative again, not that I was really

expecting anything different' [online trace C52]

As implied earlier, finding the correct and prosperous form of treatment is not a simple feat. Most of the patient stories state that they have participated in several forms of medically assisted reproductive treatments, ranging from medication, hormonal stimulation, insemination to ICSI or IVF cycles. Conversations unveiled that while there is a strict protocol and order to these procedures, according to patient accounts some aspects of the Hungarian health care practices will allow for deviation from these rigorous rules. Based on their experiences patients report that financial factors (public or private funded treatments) influence treatment order and options.

'I still hope that you will not give up, at 40 you still have a shot at trying again! (I am also above forty), but it is true that they do not welcome you for insemination at public clinics anymore.' [online trace C1181]

This notion will be detailed later in the thematic analysis section of the dissertation. International research (e.g., Perrotta, 2015) has also speculated that there is a push towards the more complex (physically and emotionally more taxing) procedures such as IVF in order to achieve higher success rates (and more income) at fertility clinics.

8.1.2. Displayed emotions and their identified triggers

Emotions identified in this section of the netnography differ greatly from those exhibited in public, or in the non-patient-peer comment sections, when reacting to for example negative religious opinions, or changes in policy on childcare or medically assisted reproduction. Not only are these emotions differing in their complexity, but also have different roots, are triggered by divergent events. Emotions on this small scale are rarely rooted in, or originating from social, moral, or political convictions, they are rather based on actual first-hand lived experiences of patients seeking medically assisted reproduction.

As it was introduced in the earlier theoretical section of the dissertation infertility and partaking in treatment can be interpreted as a biographical disruption (Bury, 1982; Engman, 2019). Due to the significant disruption in the planned life-course we can expect the emotions motivating and represented in the online traces to be volatile, complex, and diverse in their range. Investigated in the following paragraphs are these displayed emotions, and their online articulations. As we can see these emotions are not set in stone,

they are in constant flux based on the patients' experiences and the context they emerge in. The displayed feelings are considerably influenced by the reactions of those surrounding the patients, and the dynamics of these intimate, familial, and social relationships. (The topic relating to relationships are investigated in a separate subchapter of the dissertation).

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.

During the small-scale netnographic analysis seven main emotional tones were specified to typify the posts. These respective tones were: (1) angry, (2) hopeless, (3) optimistic, (4) pessimistic, (5) wishful, (6) worrisome, and (7) perplexed/confused.³⁹

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. These identified tones had a much greater personal root than the emotional engagement that can be derived from the holistic (large-scale) netnography (Bauer, nd). It can be said that while both discourses are emotional, the trigger points diverge, just as the main themes and topics do. While social and moral implications of technology and policy, along with negative views expressed by religious leaders have caused vehement and highly impassioned responses in the whole of the public online sphere, foremost these reactions do not (or rarely) come from personal experience. The convictions and expressions may be strong, but they do not stem from wrenching personal struggles, experienced loss, pain, or joy. The personal stories showing a complex heat-map of lived-experience based feelings and sentiments are reserved primarily for peer-to-peer discussion communities bound together by their common goals and struggles.

Interestingly, the angry tone in writing was confined only to those posts that were

³⁹ While the thematic coding of the online data was multi-dimensional (the thematic clusters introduced in Chapter 8.2 of the thesis), the tonality of the online trace was grabbed by identifying the main tone. The reasoning behind this operational decision was based on immersion in the data during the pilot research phase and realizing that the sentiment of the post or comment overwhelmingly represented one tone.

about the inefficiency of the Hungarian health care system, or the posts criticizing the intent of the medical experts, mainly perceptions of profit-oriented doctors. Anger was not a primary emotion identified in the context of moral or social issues, like access for single women and same sex couples, while these sentiments can be identified in a large-scale holistic analysis. Also, there was no critical anger expressed towards more controversial concepts such as spare embryos, or sex selection. As we will see in this research prong's thematic analysis these topics rarely even appeared in the discussion-group based discourses. In fact, anger towards any perceived injustice was only displayed when it came to discussing material aspects and the access limitations caused by them. In these instances, one of the main underlying forces for emotional volatility identified was the different access and care received in public and private funded treatments.

The tonality of patients' description of their own conditions showed significant dependence on their position in the above detailed patient pathways. In the initial stages, when diagnosed the emotional range was varied from optimistic and wishful, through perplexed to hopeless. Accounts showed that for some authors actually finally getting a proper diagnosis unburdened them and put an end to their guesswork. Some patients describe their initial relief after years of struggle:

'I remember that the worse part was at the very beginning, when we were still just trying without any medical help. I still did not want to admit that we had a problem and every month I just felt a huge disappointment...then we got some hope...you can imagine the excitement I started shooting myself the Puregon...from grief to running marathons everything has specific phases, and now I think I can see clearly the stages for infertility as well (I know many of you don't like this word, and I try not to use it on others, but it describes our situation well. So far after 2,5 years of trying I am still not pregnant even after all the medical help, so we are an infertile couple, of course this does not mean things can't change.' [online trace C52]

In this sense when describing their initial hopes in the technological advancements the tone was foremost optimistic, expressing wishes for wanting to become mothers as soon as possible. Of course, coming to terms with their infertility often caused confusion and worrisome, sad tones. Few accounts mentioned stigmas and carried a sort of punishment narrative.

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 pessimism, used only in the case when something went dramatically wrong. The hopeless tone was the most intensive one

identified and compared to the also negative pessimistic tone showed deeper sorrow and raised questions with the effectiveness and the usefulness of the entire process. Hopelessness was observed in those accounts where the patient seemed to be stuck in an unsuccessful cycle type treatment pathway (see above).

'I'm totally out of my mind, my life is worthless, they took away my chances for a whole family.' [online trace F1]

'I'm more and more disappointed, I can't even believe in the success any more. :(' [online trace C120]

'I don't know where to go on, everything is so messed up in me. ☹' [online trace H28]

'Somehow I don't feel anything, I think I gave up.' [online trace F71]

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 and frequently in the posts the sense of this longing was present throughout the entire analysed period.

'You are sweet but what would be the best if this were natural for everybody. What beautiful world we would live in! ☺' [online trace H574]

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.

'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.' [online trace H580]

Lack of information, the abundance of contradictory knowledges, or the toll of making tough decisions caused the perplexed tone of patient accounts. As was identified in the medical sociology part of the theoretical framework chapter of the thesis, through delegated biopolitics patients are faced with making complex decisions about medical treatments, they may not be equipped for based on their knowledge (both medicinal and ethical) (Memmi, 2012). This type of confusion could be identified in the analysed online texts as well as in the patient interviews. The role of delegated biopolitics in ethical decision making was studied rigorously by Vicsek and colleagues, including the author of this thesis (Vicsek, Bauer and Szolnoki, 2019; Vicsek, Sándor and Bauer, 2021).

It is worth to note that the online sphere has the tendency to be highly negative and the expressed opinions overwhelmingly critical. These online discussion

communities allow the emotional patients to vent their frustrations and detail their bad experiences. So by and large with a handful of exceptions (where they comment on the professional expertise of doctors following successful treatments or emphasizing outstanding bedside manners) there is really less space for the positive tones. Additionally, the passive methodological nature of netnography allows for unrestricted flow of elevated emotions, which may have been softened or quelled during the patient interviews.

This is supported by the fact that there were more positive experiences and complements of the professionals' expertise registered from the offline data. This is a crucial difference derived from the patient interviews, they illustrate that there is room for positive attitudes and opinions that do not stem from treatment success. This highlights two important aspects that need to be taken into consideration when interpreting and making methodological conclusions: (1) online data will be inherently negative and has to be interpreted as such; (2) the active researcher presence and interaction during the interviews to some extent dampen the expression of emotional volatility and limit ventilation against medical professionals. This self-restriction on the part of the patients is not seen in the online fieldwork.

8.1.3. Participants and conversation group dynamics

Gendered genetic responsibility introduced in the theoretical chapters (e.g., Locock and Alexander, 2006; Reed, 2009; 2012) can be spotted in the analysis of the online discussions, seeing that online forum participants are unilaterally made up of female patients.

Though the female participants vary among several characteristics (discussed either in their introductions, or communicated as context to their comments), they share a common bond, through their will to conceive and carry out a child with the help of assisted reproduction. This may seem to be an abstract bond, analysis of the online traces shows that these online communities can provide strong emotional and informational support and form lasting bonds amongst the authors (this resonates with findings of Cotten and Gupta, 2004; Eysenbach et al., 2004; Markham, 1998; Nettleton et al. 2005; Tanis 2008 who also investigated the role of online patient peer-relationships in support or informational communities).

The participants have built up their own communities, where they can discuss openly all their experiences and questions regarding assisted reproduction. 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. Extensive strength of these online communities is demonstrated by their continuous communication and staying connected. According to their accounts they check in on the flow of messages several times a day and also proceed to inform other members if they plan to be absent from the conversation even for a few days.

The communication shows no signs of intended asymmetry, there was no hierarchy observed within the groups of participants. They even illustrated this fact with referencing how communication amongst themselves is different from the hierarchical and formal communication experienced when interacting with medical professionals. While this finding is in itself not a surprise but looking it from a step back, it illustrates one of their main problems with the formalized doctor-patient relationship. A relationship where they feel lacking on the one hand adequate flow of information, and on the other hand absence of emotional presence, compassion, and support. And while these feelings of shortcomings of the health care professionals may also stem from failure of conceiving in a taxing cyclical treatment path, or heightened sensitivity due to feelings of loss or grief, or hormonal stimulation it signals a considerable problem for infertility professionals (a more detailed evaluation of problems experienced during the infertility treatment process and research-based recommendations for professionals can be found in Bauer and Pálóczi (2018)).

Despite the discussion communities having an established and strong core-bond, a remarkably close virtual relationship, they are rather open and supporting towards newcomers. One typical virtual trace evidence of this close and supportive group archetype was that the members did not show any signs of harboured jealousy towards each other and exhibited only caring and supportive stances towards members of their “inside group”.

‘I see that are several February inseminies. I wish everyone luck, I support everyone!!! I will come more often to talk about the developments, and I want to see how you are doing 😊 I still don’t know what I will be stimulated with, I will find out on Tuesday’ [online trace C54]

On the other hand, this illustrated symmetric group dynamic was not registered when it came to members of the “outside group”. The definition of “outside group” in this context were familial or social relationships fostered by the patients participating in the conversations. In this sample the question of inside or outside is much more complex than that of simply being a member of the conversation community or not. Their categorization dealt with whether the person could conceive naturally and easily or had to go through the tough process that has led to the application of one of the assisted reproductive technologies. 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.

A deep demarcation-line could be observed that divided aforementioned two groups, and both the tone and the sentiment of the conversations were different between members of the inner and outer groups. The participants of course did not harbour any ill will towards these women, but notions of jealousy were detected and there was a visible shift in tone when discussing them, as can be clearly observed in the patient accounts portrayed below:

‘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.:’([online trace H232]

‘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 (...) it does not make it any easier that everyday there is a birth around me... 😞 but I try to stay strong’ [online trace C1288]

The above change in emotional and interactional disposition is one of the traits generally true to online communication according to Wallace (2006).

Another type of “inner group” and “outer group” categorization is also appearing in the online conversations. Here the distinction lays between the patients (“inner group”) and those offering them treatments, the “outer group” of medical professionals. While this grouping stands out from the online traces the identified characteristics and portrayed emotions stem from different contexts to what has been introduced before.

There is significantly more conflict identified between the patient inner and the

professional outer groups. The group dynamics are more divergent than cohesive, with the highly asymmetric nature in the interactions of the two clusters emphasized. When looking at this type of unbalanced power and communication dynamics from a theoretical perspective, it is important to keep in mind that while there has been a relevant balancing out observable in the professional-patient relationships, the nature of the interactions is less cooperative or patient-centred than members of the identified “inner group” would prefer⁴⁰.

8.1.4. Language used amongst patient conversation participants

The participants of these discussion communities seem to have developed and adapted their own terminologies, their own language, one that might seem odd to non-participants, researchers, or total outsiders⁴¹. The hyper-formal, text-book 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 way of expression possibly adds a sense of friendliness to these cold medical terms, and some of the abbreviations make both the communication process, and the comprehension easier. A comprehensive list of the new terminology, their medical counterparts and English language translations can be found in the Appendix of the dissertation⁴². A handful of examples for softening devices – “*beülti*” (*embryo transfer*); “*fagyibaba*” (*vitriified embryo*), “*stimu*” (*hormonal ovarian stimulation*); “*leadta a fiúkat*” (*partner gave a sperm sample for testing*).

This type of communication does not necessarily mean that the authors do not know or comprehend the correct terminology. Having accumulated a significantly grounded base of knowledge, and in many cases developing lay expertise implies that these “friendly words” are more in tune with the emotions than the knowledge level of participants.

Thus, apart from the comforting role of softening linguistic devices, these special

⁴⁰ The characteristics of doctor-patient relationship dyad are introduced in detail earlier in Chapter 3.3. of the dissertation.

⁴¹ Similar linguistic tendencies were observed by Veszelszki (2020) in relation to the pandemic and the lock-downs.

⁴² Words and phrases from this patient language were also added to the complex keyword syntaxes described in the Data and methods section (Chapter 7), and they can also be found in the Appendix of the thesis.

words and phrases also have other identified functional dimensions. They serve as tools for knowledge transfer for those who are less armoured with contextual expertise or are new to the world of medically assisted reproduction. In this sense the more knowledgeable authors adapt a type of ‘translator role’ to make the terms comprehensible. In line with theoretical notions this granular immersion of the topic can be interpreted as a representation and expression of their ‘lay expertise’⁴³.

When considering both above mentioned functions, a third role of the phrases can be argued. The words are symbolic representations of the distinctions between the prior subchapter’s group cohesion – a communicative construction of the “inner” and “outer” realms. One must be connected to the “inner group” to understand their special language. Through these communication tools the line of demarcation is deepened between the inner and outer groups.

From the patient interview strand of the multimethod research further evidence of the cohesion creation function of the special terminology can be deciphered. Use of the special phrases was almost completely reserved for the “inner group” online conversations and appeared only sporadically and marginally in the offline data. An explanation for this can be that the active researcher presence (researchers belonging to the “outer circle”) triggered more formal language use and that these phrases were reserved for conversations with fellow patients. When they did appear (mainly naming the embryos) there was usually an explanation attached to these words, and the patients assumed their translator roles and relied on their experiences of visual representations of the embryos – their contextual knowledge. These words depict relatable and visually similar objects, all the while expressing care and bonding connection towards the “growing” embryos as can be seen in the following phrases: “*szedrecskéim*”, “*eprecskéim*”, “*faltjaim*” (*my little berries, or my smudges*). These kind words show feelings of motherhood and the instinct to protect from the first moment. The theme of motherhood is discussed at length in upcoming section, Chapter 8.2.3. of the dissertation.

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

⁴³ The concepts and dimensions of lay expertise are introduced in Chapter 3.2.3. of the thesis.

frustration (these are to lesser extent) at the process, institutions and policy concerning assisted reproduction, (3) pictograms representing gender and womanhood, and (4) emojis illustrating pregnancy and babies.

8.2. The map of the conversation – results from the thematic analysis

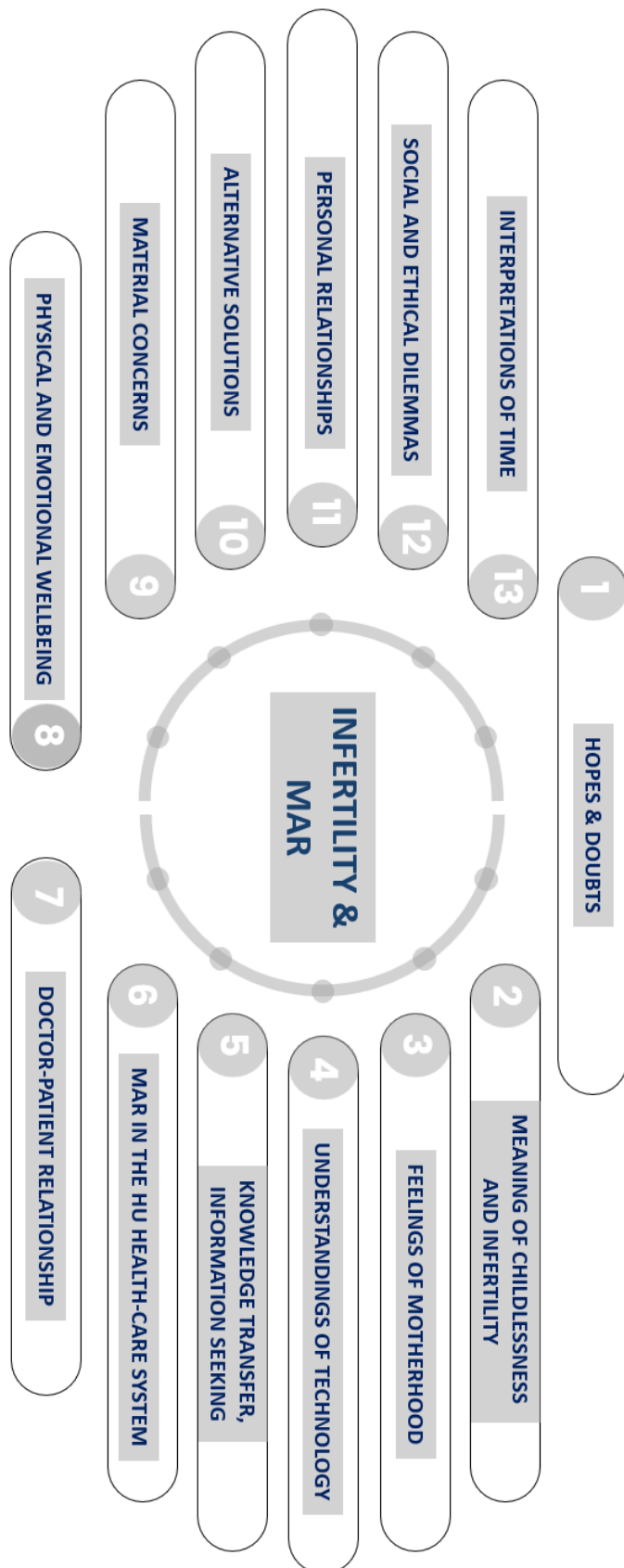
On the following pages of the thesis introduces a mapping of the narratives appearing in the online traces. This portrayal of the conversation illustrates the identified themes and topics structuring the online conversations. In addition, the following narrative map also serves as a guide for the reporting of the thematic analysis of the research – thus the subsequent parts of the thesis will introduce the identified themes and the topics within each theme in detail⁴⁴.

As the map shows thirteen main themes were identified, each overarching several discussion topics. The established main themes 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*.

The introduction of these themes follow the Braun and Clarke's (2006) guidance on thematic analysis⁴⁵, looking at the theme from six perspectives: (1) meaning; (2) underpinning assumptions; (3) implications; (4) conditions triggered appearance (5) why is it represented as such in the data set; (6) relation of the theme to the overall story of the research topics.

⁴⁴ Parts of the results chapter rely to some extent (at times heavily) on previous works of the author, adapting some frameworks and results from the pilot research (Bauer 2013; 2014; 2015). The shown analysis will foremost rely on the results unveiled by the small-scale netnography, but it will be complemented by results from the analysis of the patient interviews as described earlier in the methods part of the dissertation.

⁴⁵ The adopted approach to thematic analysis is described in Chapter 7.5, foremost relying on the systematic overview of Braun and Clarke (2006) augmented with other practical considerations from other methodological experts.



17. Figure: The narrative map of the Hungarian online medically assisted reproduction conversation

8.2.1. Hopes and doubts

Hopes and doubts is an integrative, overarching theme dealing with the emotional spectrum of participants, interpretations of their chances with medically assisted reproduction. With all elements reoccurring also in other identified themes.

In an earlier part Chapter 8.1.2. we could see while the overall online conversation portraying negativity, a more nuanced topical investigation needs to be conducted. With the theme Hopes & doubts a mostly optimistic and enthusiastic view of medically assisted reproductive treatment was portrayed.

Hope is portrayed mainly towards technology, the process of medically assisted reproduction itself. Authors see it as a last way, last resort to ease out the disruptions in their life-course, as illustrated in the comment below:

'We tried for years, nothing this is the only way for us to have a family. but it will work this time, I know it, I can feel it. They must be sticking, they must be sticking.' [online trace F85]

The above quote also shows the need for normalizing their biographies, to achieve what comes naturally for others. Hopes to overcome lacking and inadequacy are detailed in the subsequent part introducing the infertility narratives. The fact that authors feel that medically assisted reproduction is their only option for family formation (neglecting the thought of adoption, fostering) mirrors Hungarian society's emphasis on biologically, genetically related children (as detailed in Chapter 5 of the dissertation), and the focused aim of normalization of the disrupted life-course highlights the incorporation of the pronatalist ideology appearing on a micro and macro level.

The doubts expressed could best be interpreted as fears and were interlinked with their opinion of the Hungarian health care system. From a psychological perspective, doubt can also be interpreted as a portrayal of their own mistakes, sins and faulty abilities (also introduced in subsequent narratives). There are only limited traces touching upon doubts in the technology itself (they see it as beneficial for themselves and women in general – with no moralizing), but fears are expressed about potential side-effects and long-term problems.

8.2.2. Meaning of childlessness and infertility

The second identified theme is rather complex, with manifold subtopics and varied emotions connected to the experience of involuntarily not having children and being diagnosed as infertile. The theme dealing with these experiences are highly emotional and very much influenced by the situation of the patient (intricately linked to their position on the infertility patient pathways detailed in Chapter 8.1.1.). The chunk of data items belonging to this theme navigate the reader in understanding the patients' interpretation of their own involuntary childlessness, while expression of these emotions and understandings can be a form of coping for patients joining the online communities. Their expressions represent a constant battle against forces of nature, marred with experiences of sorrow and grief, and an isolation from their surroundings (micro and macro). Coded for this theme are those online traces and interview parts that offer a glimpse into what and how patients describe and interpret their own conception problems.

In this section the identified theme will be analysed first from the narrative perspectives of the authors, and then other subtopics from the theme will be introduced. The identified narratives of the theme shed light on the feelings of the authors, and how they see their situations, while the examining of the subtopics discuss what they think of motherhood and alternatives to becoming biological parents.

As both the theoretical and empirical literature introduced has established that involuntary childlessness and infertility are highly undesired and emotionally taxing states, especially in traditional family centric, pronatalist societies as is Hungary (Cserepes et al., 2014; Mata, Boga and Bakonyi, 2001; Verhaak et al., 2006). The netnography has unveiled five major narratives in the conversations, and one that only appeared temporarily, when it was triggered by negative comments made by a leader in the Hungarian Catholic church, which was analysed at greater length in the previous chapter. This section goes on to introduce these narratives: (1) punishment; (2) inadequacy & stigmatization; (3) illness; (4) loss and grief; (5) warrior + (6) "bad Christian". When comparing these to the interview data we can observe that because patients are controlling themselves more in an offline interactional situation with the interviewer (and the missing comfort of the supportive "inner group" induced comfort documented in Chapter 8.1.3.) and focusing more on the technical details they are more

comfortable sharing, the expressed emotional narrative spectrum is less nuanced, and to the most part less volatile and personal.

8.2.2.1. Punishment narrative

Some patient authors see their situation as a sort of punishment. This can be a punishment for their earlier decisions – such as career pursuit, or not wanting a baby (having an abortion, or using contraceptives for a long time). This narrative mirrors those micro- and macro-level opinions, which place the blame on women for lack of family formation or having the desired number of children. Some authors have highlighted that they spent a long part of their fertile years achieving other goals and the desire and priority for family came along when they were already at the life-stage when the chances of conceiving naturally are in decline biologically. While self-blame is expressed, it is softened by belief and hopes in medical solutions and technology.

‘everybody has their own reasons for starting this whole trying to have a child thing late. Some because of their career, but I think many for different reasons, and many start facing it at 40, that wow how stupid I was that I spent my time with this and that. Unfortunately you cannot turn back time, and if it is one year, then it is one year’ [online trace C516]⁴⁶

In a few cases it emerged that it was not their life-course decisions that they felt wrong, but how and where they decided to enter into treatment. An exceptionally bad experience can lead to termination of treatment cycles and staying away from MAR until the success-rates of the processes are significantly lower. Only extremely bad experiences were reported as being ultimate deterrents from treatments. It is interesting that while anger and disappointment is expressed towards the specialist who failed with the treatment⁴⁷, they also lash out at themselves for opting for MAR solutions to quickly or without proper consideration, as highlighted in the following comment-fragment:

‘The earlier treatment destroyed me emotionally so much, that I did not start another program for 8 years. Today, now I know that this was a huge mistake, until now there was nothing wrong with me and now my ovaries are slow, this is what we started with again, my partner’s results are catastrophic too.’ [online trace C885]

Amongst those who may be religious there were a handful of comments searching for the connection between their infertility as a kind of punishment from above, from

⁴⁶ The verbatim are given a unique code to use as reference numbers, for anonymity. The construction and assignment of the codes has been done by the author of the thesis.

⁴⁷ This type of frustration will be detailed in Chapter 8.4., where the relationship of doctor and patient is examined rigorously.

God. This type of reasoning not only alludes to the concept of worthiness and self-worth, but also highlights biological and social unjustness in the context of who can be blessed by motherhood. The below comment not only exemplifies the punishment narrative but is parallelly a good example of how the yearning for motherhood is expressed in discussion communities.

'I just realized something. I realized that God (or fate) is blind!!! Dear God! I know your eyes are bad, because you cant see all these yearning hearts, who are waiting only to become mothers. Your eyes must be bad, because you give those women children, who will just throw them in a plastic bag in the dumpster' [online trace C393]

It is compelling in this punishment type of explanation, that it looks at infertility as a situation that can be rectified by “acting worthy” or some sort of individual repentance. This was foremost expressed as a form of life-style alterations, self-betterment, coinciding with the ‘Adapting life-style’ stage of all patient pathways. It was observed in both netnography and interviews that after the initial diagnosis couples decided to “get their acts together”, to make their bodies healthier, better prepared for the treatments.

'so we were in this very interesting mental state before starting. We knew we were starting, so we began to eat healthy, I started to work out, lost about 7-8 kilos. My husband worked out too, we did not eat anything bad, so I think our success was partly because we prepared for it so knowingly.' [patient interview D001]

*'we started at it differently second time around. we knew where we were, what we had to do. Everything was checked out, I did yoga and said f** no to everything stressful' [online trace F192]*

While at the forefront of this behavioural change was adapting their physical qualities, getting psychologically prepared to “accept treatment” (“to be ready for motherhood both physically and emotionally” [online trace C995]) was also highlighted by several participants. This intentional preparation also illustrates that the patients know a about the biological and physical barriers of conception and have accumulated knowledge about what they can do for better chances of having a baby. The role of knowledge in medically assisted reproduction is explained thoroughly in Chapter 8.3. of the dissertation.

8.2.2.2. Inadequacy & stigmatization

The stigma of childlessness burdens foremost women, they are the ones assuming

a larger part of the genetic responsibility, this could be seen in the introduced literature (Chapter 3.4). In the analysis of the online conversations there were several feelings and experiences connected to this narrative. The online accounts of the participating women reflect feelings of weakness and insecurity, alongside feelings of diminished femininity.

'I feel like a huge nothing because I cant get pregnant'[online trace F87]

'(...) unfortunately I bled and we were unsuccessful again. Daddy is hopeful, but I gave up. This has been going on for 9 months now. 😞 Why won't it happen? I gave birth two and a half years ago, and daddy also has children from another marriage...I have crumbled, Daddy thinks WE ARE MIRACLES OF THE WORLD! But I am no miracle 😞...' [online trace C719]

These feelings of being “less of a woman” (or as illustrated above being “no miracle”) are escalated when there is a visible pregnancy or news of conception in the family, at the workplace, or even in a larger social network. In these cases, their negative feelings towards themselves are transposed onto those who are able to conceive. Arguments are made about not having proper bodily agency, of not being in control of their bodies, being overall powerless. Patients are showing a complex disposition of feeling socially (or in their hearts) obligated to be happy, but at the same time harbouring jealousy. This type of cognitive dissonance is mostly only implied, but one author expressed it explicitly as follows:

'There will be another baby in the family, the first boy is just 4 months from my J.. There will be only a year and a half between the two boys. I became so envious I can't even begin to tell you! They planned it, this is how they wanted it, and they made it! (...) It's the possibility I envy the most.' [online trace C504]

Explicit stigmatization can be felt by direct shaming from family or community as expressed in online trace C1099:

'just because someone can't get pregnant you do not have to retell them "IT IS YOUR FAULT!!! They have enough problems as is without someone shouting at them they are responsible. Just because you were lucky it does not mean all are.' [online trace C1099]

More often though, feelings of inadequacy can be triggered by just being neglected or shunned by “looks”, “stares” and “side-way glances” reported by many patients.

The below comment-fragment elucidates how women socialized to do so, take the genetic and reproductive burden upon themselves instinctively, even when their community is supportive.

'With us it is me who has the problem, and I felt this for a long time, its very hard to get over the feeling that you are at fault. You feel this every month when you get your period and realize this after each cycle, and this can be really hard on the emotions and your partner too' [online trace F1383]

All the above-mentioned experiences lead to feelings of loneliness, and alienation from surroundings. The support provided by the online group helps participants deal with these feelings of social isolation and stigmatization by giving emotional support and also by showing the women that they are not alone in their situation. This type of cohesion between members of the “inner group” as opposed to the outer group has been detailed in Chapter 8.1.3., where factors facilitating bonding were explained.

As infertility and assisted reproduction is still considered a taboo, something not to be openly discussed⁴⁸, participants marvel when they find out that so many others are in the same shoes and are comforted when understanding that others also feel the same emotional volatility and personal shortcomings.

Authors of online discussion communities focused foremost on their own emotions. In contrast, during the interviews thoughts about male infertility are also described by the women. During the offline patient inquiries, it appeared in several reports that the medical problem was with the partner, and these women reflected on their partners' behaviour and feelings. Some interviewed patients discussed, how their partners and men in general also struggle with fears of social stigmatization and deep feelings of inadequacy.

'when we got pregnant after so many years and procedures I could see that it was a big success for him to go to his work and say that he had a son, but I saw on him like he had been replaced, this is a huge psychological burden for men, if they can't make a child' [patient interview D001]

As demonstrated, the emotions and reactions of their husbands were portrayed with empathy, emphasizing the same social burdens that caused women distress.

8.2.2.3. Illness narrative

The illness narrative is very much intertwined in the online texts with the above-described social alienation and self-isolation. The narrative appears constantly throughout

⁴⁸ Hungarian society is rather traditional, and the importance of biologically related children is rather high. Moreover, during the last decades while there have been highly publicized arguments about the importance of fertility from a demographic perspective, public debates or even education around medically assisted reproduction, and its opportunities have been rather scarce.

the stages of the patient treatment pathway. Firstly, patients report about a perpetual cloud of illness related anxiety (and the restlessness of knowing that there is something very wrong) throughout all the testing protocols. The patients live in a consistent state of angst, their entire life is disrupted waiting for test results, more tests and what seems like a never-ending stream of medical events and procedures.

'You wait and wait and wait. Go to the tests, do the motions, go to the doctor, come home, shoot the hormones, do the process and then it starts again. You just wait and wait and wait.' [online trace C678]

Throughout the before treatment waiting and also later while the cycles are performed (a typical description shown above), patients report that they are constantly paying attention to their bodies, looking for signs, reactions and even the slightest of symptoms can cause days of worry and anguish.

The diagnosis can be debilitating in the beginning. Being pronounced sick is a heavy emotional burden, a loss of hope for a natural, spontaneous pregnancy. This heightened alertness of their condition is escalated by their feelings of being at the mercy of an unpredictable and slow-paced health care system. Moreover, some accounts refer to the omnipotence of medicine and doctors, and feel that they get lost in the system, become just one of the cogs in the process, without any personalization and attention to their individual, unique situation (experiences obtained in the Hungarian health care system, and the role of doctor-patient relationships will be analysed to greater extent in a later subchapter, Chapter 8.2.7. of the thematic analysis).

Interestingly, for some being diagnosed is not a source of anxiety, but of resolution.

'in the beginning I was excited, everything was new, especially after a year and a half of passivity I finally felt like we were doing something to get pregnant: bloodwork and inseminations came one after another. But by then I have overinterneted myself, I knew that the only real option would be IVF.' [online trace C52]

The author's expressed feelings of resolve highlight several dimensions. Firstly, it alludes to re-establishing some sort of control and again experiencing agency, their ability to influence their situation. Secondly the quotation exemplifies the research-work patients do to gather knowledge about their conditions. Finally, it also highlights the belief popular amongst patients that IVF is the only appropriate solution for infertility. This typical way of interpreting and (mis)understanding technology is explained later in the dissertation,

in Chapter 8.2.4.

8.2.2.4. Loss and grief narrative

Involuntary childlessness and the assisted reproduction treatment pathway are often marred by horrible patient experiences (some of these are reported on in great detail in the online data, and to lesser extent in the offline patient interviews). These “verbalized” experiences include extended periods of trying to conceive without success, which some patients describe as “*monthly loss of children*” or “*monthly loss of opportunity*” (‘*every month I die a little*’ [online trace F2523]).

Many authors have described having a number of failed ART treatments, along with multiple miscarriages, one of the profoundly emotional comments is quoted below:

‘what do they know? I will start again in six weeks, idiots. the sixth week came, and lethargy and depression, lets wait some more, Then came the thought, I don’t want to have any children never in a million years again. Not one. I had two, the little angels who will never come back. I think only now did I get to the point of being able to let them go.’
[online trace C77]

All if these are forms of both individual and family tragedies and crisis, accompanied by emotions reflecting sadness, defeat and grief. Some patient accounts describe in great detail how these continuous losses cumulate resulting in utter despair, loss of hope and giving up. Childlessness in this narrative means tragedy, pain, and suffering. The narrative of loss and grief is deeply intertwined with other identified, priorly introduced narratives of punishment, inadequacy, and illness.

8.2.2.5. Warrior narrative

Whilst for some patients the extended treatment cycles, and the continued failures resulted in deep depression or giving up, for many it channelled unprecedented inner strength. Moreover, in the portrayed warrior narrative childlessness is the enemy and the treatment path is a constant battle, a war where the counterpart must be defeated (‘*I have already started my battleplan*’ [online trace C117]). The warrior narrative explicitly uses the war metaphor to describe their struggles (“*little fighters, little warriors*”).

‘Come hell or high water, I will not give up my dreams, my hopes and my happiness! My

dream is to become a mother!’ [online trace C42]

‘I had three ivfs and three miscarriages..., 5 insems and 2 miscarriages, but I will fight till I become a mother!!! YOU CAN NEVER GIVE UP!!!’ [online trace C27]

Comments from patients adapting a warrior-like attitude portray following: (1) they will let nothing stand in their way; (2) they will try and do everything possible to have a child because they want so much to become a mother (see above [online trace C27; C42]); (3) they will never give up, their fight is to the very end against all odds [online trace C42]; (4) viewing infertility as an enemy to be conquered empowered most patients, giving them strength to continue their quest [online trace C117]; (5) only a few accounts were of them feeling over-extended, tired to the brink of giving up [online trace C77].

8.2.2.6. „bad Christian” narrative

Interestingly this narrative only appeared temporarily in the discussions and was always triggered by context, a comment or and opinion from a religious leader. After András Veres, Hungarian Catholic leader proclaimed assisted reproduction to be a sin, some discussions focused on the moral and ethical implications of the biomedical technology. A couple of authors felt that ART was stigmatizing in their religious community, while others were frustrated that this burden is also placed on them in addition for being proclaimed immoral for not having children in the first place. After the elevated media and online user attention surrounding these remarks (detailed in earlier chapter), this narrative disappeared from the discussion communities.

‘again those are saying things about ivf that know nothing about it and never had anything to do with it. They heard two bad stories and now they call it the work of the devil.’ [online trace C286]

The results from the interviews showed that even for those patients who proclaimed themselves religious, the thought of not participating in assisted reproduction was not an option. Some aspects of the process (i.e., vitrification, or destruction of spare embryos) did raise religious and moral concerns, but in the end, achieving pregnancy was deemed more important. (The ethical dilemmas surrounding embryos, and embryo classification was researched in detail by Vicsek and colleagues, including the author of the thesis (Vicsek and Szolnoki, 2015; Vicsek, Bauer and Szolnoki, 2019)).

8.2.3. Feelings of motherhood

The theme of motherhood is rather complex. In this section I will examine firstly the meaning of motherhood, then based on the sample, aim to pinpoint when (at what moment, or stage in the medically assisted reproductive process) participants feel they become mothers, from when do they see themselves as family.

Motherhood is a central theme in the analysed data set, and from extracts belonging to the theme, we can observe that for the participating women motherhood means biological motherhood (other types of family formation is not framed as becoming a mother in their accounts). Adoption is rarely addressed, and when it is the option disregarded completely or treated as a very last resort. This tendency of understandings of motherhood is in line with the typical Hungarian viewpoint. As mentioned earlier Hungary is a very traditional society when looking at biologically related children, which is amply supported by pronatalist government communication, regulations, and social policy decisions (Kapitány and Spéder, 2006; Szalma, 2014).

The netnography shows that there is no one fix point in the treatment pathway when women begin to feel as mothers. The “starting point” varies a great deal, depending on earlier experiences, or the emotional disposition of the patient, and even can be connected to their state of their imagination. The most conscious of patients (foremost those who have had multiple miscarriages) detach themselves until critical milestones in the pregnancy as reported by a patient below:

*‘when I peed and saw the blue strip, well that I can’t even begin to describe, but it was very heavy, but I did not feel like a mother or anything, I did not have that’
[online trace F386]*

On the other end of the spectrum are those extremely optimistic patients, who already start feelings of motherhood at the first visit, or at the stimulation, or egg retrieval. This type of information was mostly grabbed through the offline, interview prong of the research. Most women in the patient interview sample already connect motherhood to the embryo. The most common voices are of those though who have motherly feelings when they first see or realize they have produced embryos, such as one of the interviewed patients told us: *‘well, I immediately started feeling a connection, I waved at them to say, hi!’* [patient interview D12]

The visual representation of the clinics (giving patients printouts) influence this naturally as depicted to detail in Vicsek, Bauer and Szolnoki (2019). The sample's accounts state that many have named, or nicknamed their embryos, and felt protective towards them, like those duties of mothers. A good representation of this attached behaviour could be observed in patient interview D03: *'I knew that they were going to be our children, or they were our children, I see them as children'*. Attachment of patients could also be seen during talk about loss of embryos (those that did not develop properly) in the fashion that others would discuss a loss of pregnancy *'I was the mother to two little angles for a while'*.

8.2.4. Understandings of technology

Lay interpretations of technology are the focus of the theme analysed in this upcoming section. In an earlier part Chapter 8.1.1. with the theme Hopes & doubts a mostly optimistic and enthusiastic view of MAR treatment was portrayed, and the doubts expressed could best be interpreted as fears and were interlinked with their opinion of the Hungarian health care system.

The online trace data set of the netnography shows that most authors have relevant knowledge of assisted reproductive technologies, and their main characteristics. Albeit their general possession of adequate information, some patients do not necessarily have a grasp on how and why the use of these technologies typically follow a predefined medical protocol, a set order. The Hungarian regulation requires (except when medically justified) that many solutions be tried before resorting to ICSI or IVF. The medical reason behind this is that these are the most invasive procedures, while stimulation and other medicine-based treatments, or artificial insemination are less physically taxing for the patients.

The analysis of the online traces unveiled that the reason for this hierarchy is often not understood or misrepresented in the online discussion communities. Instead, they apply their own reasoning, which mainly centre around costs and time. Costs here are twofold, they are firstly the financial burdens accompanying the treatments, secondly, they are the emotional and physical tolls that the different treatment types have on the patients.

In some instances, authors recommend trying stimulation or insemination instead of the more complex IVF or ICSI because they are less invasive, but also because they are cheaper – *‘the insems are cheaper, it may be enough for you, you should try’*. (The role of money will be detailed to greater extent in a subsequent thematic section of the thesis.) The above verbatim shows how lay interpretations of technology may focus a non-medical aspect of the treatment decision, instead of advising fellow patient to follow the specific, professional recommendation of the treating physician.

Another (mis)understanding of the technological order is rooted in the context of time. Couples often wish to jump directly to IVF or ICSI instead of starting with simpler technologies, as portrayed in online trace F109: *‘if you go to the private clinic you can skip the insems and start with the ivf, that is where you will go anyway, so this saves time and dissapointment’*.

The reasoning behind this is that most couples by the time they get to infertility treatment are older than the optimal age for conception. They feel the need to bypass the insemination procedures and go straight for the more complex treatments in order to have higher chances of success. Peers recommend using private infertility facilities instead of the state-financed options, because there they are said to be more laxed with such protocols. While in the context of their reasoning saving time makes sense, medically the more invasive treatment might be unnecessary and even harmful.

8.2.5. Knowledge transfer, information seeking

In line with the earlier findings of Tanis (2008) the two most common reasons for participating in the infertility treatment related discussion groups were to access information and receive the support of others in the same shoes. In this context the online conversation communities 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 (on both treatments and professionals) based on the analysed 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

theme of knowledge and information along the infertility treatment pathway will be further detailed in the chapter discussing the patients' lay expertise.

8.2.6. Doctor-patient relationship

During the analysis of the discourse within the infertility related discussion groups it has become evident that the change in the doctor-patient relationship is expressed quite manifestly by the research subjects. This theme is detailed in a subsequent chapter of the dissertation, diving into relationships of the doctor-patient dyad, looking at the changes of its dynamics, and how the introduced theoretical models can be applied to the results of present study.

8.2.7. Medically assisted reproduction in the Hungarian health care system

As introduced above, a compelling amount of communication was about doctors, medical professionals, and their role in the Hungarian healthcare system. Online traces touching up on the two topics were categorized into two themes, based on their topic and the bringing together two lines of thought of inductive and theoretical thematic analysis.⁴⁹

These themes proved quite salient and illuminated that these issues are of core relevance to the patients communicating in online discussion communities. While the categories for doctor-patient relationship was deductively created based on the theoretical literature, issues with the Hungarian health care system itself, was a category established inductively after pilot assessment of the texts – highlighting the pertinent role of context for the analysis. The section below investigates the theme of the health care system.

While the evaluation of doctors, and other medical professionals is ambiguous, showing both the positive and the negative range of the doctor-patient relationship (but it must be kept in mind that the online data-set is very negative leaning, as the platforms

⁴⁹ A detailed introduction to the guidelines followed in thematic analysis and a review the coding stage is in Chapter 7.5. of the thesis.

serve as a venue for ventilation, and thus no real space is left for disseminating positive messages about professionals – for detail see Chapter 8.1.2.), conversations involving the health care system are consistently critical. The picture painted through the lived patient experiences about the Hungarian health care system was anything but positive (see online trace F346). The long waiting periods and the inefficiency of the health services were at the centre of critique.

‘This healthcare is just great!!! I love it!!!’ [online trace F346]

The participants also debated whether it was in fact even worth paying social security (online trace H360), when in need not receiving sufficient benefits.

‘Forget why you pay social security! We don’t ask useless questions. :D’ [online trace H360]

While the first two experiences lashed out at the whole Hungarian system, pointing out the inequalities of its mechanisms, the following verbatim illustrates a much more deeply rooted systematic and problematic view of infertility facilities (in the context of Hungarian health care.) While the earlier subtopic of the theme suggests and acknowledges that there is dysfunction in the system, this subtopic aims to offer an explanation and a source to blame. As in online trace F09, numerous comments connect the private part of infertility care to directly preying on women, knowing that they will pay as much as they have for treatment. The harshest point they make is that the clinics or professionals deliberately botch cycles to earn money.

‘So this is the situation everywhere, I mean they rip you off with money! It’s good business for them, and it is not worthwhile for them to make everyone successful on the first try!’ [online trace F09]

Pronunciation of the above opinion is quite harsh, and while it sheds light on the fragile trust between professional and patient (introduced in Chapter 3.3.1. and analyzed in following Chapter 8.4), it must be handled with caution. This type of misinformation can be extremely viral and its claims damaging to both the facilities and their patients.

The authors saw it as inevitable that if they wanted to progress quickly along the treatment pathway, they would at least have to partially finance the process themselves. They expressed concerns about how the whole set-up was to serve economic interests, instead of benefiting the infertile community.

*'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. ...obviously he has a private practice and that is what he prefers, but he also works at *** state funded, but I don't know if you can go there based on social security alone' [online trace H928]*

Resonating the thoughts illustrated above, a number of authors feel that they are inadvertently pushed towards the private branch. They end up choosing this option foremost to save time as resonated in [online trace H364]: *'its just ivf business as usual...if you don't want to wait you have to pay'*.

As illustrated in the thesis, time is a central concept of infertility and medically assisted reproduction discussions. Opting for private care helps the couples bypass the long waiting lists, state-funded mandatory steps, and makes the treatment cycles shorter. Choosing private care is also more convenient according to patient accounts. All the while the online opinions show that the participants see exactly how excluding the system is, creating barriers and excluding those with lesser financial means from a swift process. Still with all this being said, it is important to mention that Hungary has a very generous funding scheme compared to other countries (even before the new nationalisation and cost cutting policy measures introduced for 2020, and 2022) (ESHRE, 2020).

Based on patient accounts, the conduct of the medical staff in private clinics or in the private funded programs of hybrid clinics is also better. As they explain, at the private facilities there is ample time to pose questions, ponder solutions, and the doctors and nurses are patient, do not rush. They show the empathy that the emotional patients would consider to be a must for all prongs of health care. Again, generalizations made from these emotion-based responses must be treated with caution, projected feelings and hope have to be taken into consideration, as well as cognitive dissonance reduction amongst patients with failed state financed treatment cycles.

The most extreme of the elaborated notions is that the entire Hungarian health care system is inadequate appears in the conversation quite regularly. It was not an uncommon idea that after severe disappointment that they would go abroad to receive treatment⁵⁰.

⁵⁰ Numerous mainstream media articles were published recently (after the timeframe of the research) about how many Hungarian couples plan to go abroad for infertility treatments after the nationalization of the Hungarian clinics – so an important topic for future research can be IVF-tourism of Hungarian patients to Czechia, Denmark, Austria, Slovakia, and Romania.

8.2.8. Material concerns, financial burdens

The theme of financial burdens is inseparable from the prior themes dealing with the health care system, and the supposed malicious intent of doctors. The subtopics of costs, economic hardships, and how financial constraints were one of the main limitations to participating in further cycles was discussed in great depth. Traditionally it can be stated that Hungarians are much concerned with financial issues, and the material dimensions of other illnesses also play a role in our society. But with assisted reproduction the hybrid financing of the treatments, the hybrid forms of the clinics (and the opportunity for patients to cross-over at any point of the treatment pathway given they possess the financial background to support the decision) brings the issue to the forefront of patient interest.

While this in itself is a relevant knowledge about how patients appreciate our domestic healthcare, for the purpose of understanding underlying mechanisms of patient desire to have children, the significance of the theme lays in the fact that it takes quite an enormous effort for the patients to produce the resources needed for the treatments. The story below (from online trace C931) does not stand out, a pattern emerges in the dataset showing us how devoted the patients are towards having a child, how this is their sole focus, to achieve this they are willing to make ample sacrifice.

'we waited 8 years for our first ivf and this was mostly because of the money. So much money went into this throughout the years that I had to sell my car and all of it went on this and even more' [online trace C931]

In context of the entire thematic realm of the dataset the above verbatim also relates to the meaning of motherhood, and implicitly touches upon the previously introduced warrior narrative.

Even if the couple chose the state funded treatments the cost of medication was rather high, could reach up to six figure amounts. Detailed accounts were introduced to show the personal sacrifices made to be able to have children with the use of assisted reproductive technologies. It is important to note that at the time of the research most of the medications and supplements prescribed during assisted reproduction were not fully funded by the state. At the end of the research period legislation was introduced about providing full state funding for some of the medications (detailed in earlier chapter

dealing with the Hungarian context of the research – Chapter 5.), but the discussion communities have up to the time of the data collection did not have first-hand experiences with this, they were still searching for the information. The financial burden of medications was one of the major implications discussed in a position paper for stakeholders written with the contribution of the author of this thesis (Bauer and Pálóczi, 2018).

The material concerns were often paired with concerns about the general state of the Hungarian healthcare system. Patients accounts tell us that when having participated in both types of treatments, they felt that private funding also bought them better care and facilities, as illustrated by the emotional and angry online comments below.

*‘The state funded is only good for not letting you bleed out on the floor’
[online trace H862]*

*‘We went full private. We did not have to wait. We had three cycles in half a year, but you have to pay for everything, there is no social security financing involved.’
[online trace C1233]*

The prior two comments were part of a larger debate about where they can get better and even more important, start the cycles as soon as possible, and to find a solution that allows for them to bypass waiting lists and *‘unnecessary treatment stages’*⁵¹.

Parallel to the above (where the clinics were addressed as a problem source), the depicted theme also involves content debating the role of the professionals. The below verbatim highlight again how central financing and having enough money to achieve their goal is to the patients.

‘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. [online trace F33]

Intent of the doctors was also questioned by the patients in the context of financial hardship and inequality, going as far as stating the doctors give special attention to those patients able to give them extra money, and neglecting those patients who do not have the resources to do so.

‘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

⁵¹ Chapter 8.2.4. elaborates on lay understandings of technology and processes.

clinics. ☹' [online trace F299]

'he does not like her, but she tries avoid his private practice and use the social security financed things...well it did not work. Money is an important master' [online trace C650]

As introduced earlier ethical and moral concerns are not at the centre of medically assisted reproduction online discussion. Some concerns were shared amongst conversation participants, but they were almost exclusively only expressing concerns of inequalities through their own economic hardship. The analysed texts showed a great deal of communication based on their own situations, but the participants mostly did not express worry or interest in the exclusion of others, only a handful of instances were captured when they made abstractions, the other times they discuss their own situations as can be observed in the traces from a same thread.

'Well yes, if someone doesn't have money they can just go in the gutter.' [online trace H438]

'Oh my, that is not little money .It is good that there is three month between cycle, we can get ourselves together a bit.' [online trace H404]

'Yes until there is proof in your hands it feels like money thrown out the window.' [online trace H351]

Recent legal changes (including the funding of the necessary medications and supplements), and proposed nationalizations are said to aim to break down these financial barriers of access, but discussion groups have not addressed these questions.

8.2.9. Physical and emotional wellbeing

A large portion of the discussion belonged to the theme of physical and emotional wellbeing. The theme encompasses subtopics foremost focusing on the side-effects of the treatments. Although overwhelmingly mainly negative side effects were discussed, even the worse ones did not dissuade the patients from continuing on their paths, again reiterating the elevated importance of becoming a mother (of their own genetically related child(ren)). Mostly the side effects of the hormonal treatments were discussed. As mentioned earlier, patients felt that they needed to prepare their body for the treatments, to accept the pregnancy.

“we went to the dentist, to make sure everything was as it should be. Also took a vacation before jumping into it, so we could be nice and relaxed. You need to take a break, it’s a good thing it was summer.” [online trace F192]

As shown in the above verbatim the preparation showed to be almost ritualistic, a way to gather the positive energies, and leave the old negative experiences behind. The aspect of the theme deeply intertwined in the punishment narrative introduced in Chapter 8.2.2. and the reported interpretations of “worthiness” or “becoming worthy” after being punished for earlier behaviour.

Some patients expressed the importance of also adequately preparing the psyche. In agreement with other group members, one vocal patient expressed the value of coming to terms with one’s conditions and being able to accept the situation as shown below.

‘Since summer I feel I must believe in psychological infertility as well and that a few conversations with a psychiatrist who knows the subject can put things into place in your head and can release you from a lot of anxiety and also help you communicate better with your partner. I think I would recommend this as a supplementary 3+1 treatment’ [online trace C41]

Their interpretations and “translations” of psychological tenets focused on preparing to accept the embryo, and meanwhile preparing for motherhood.

The initial assumption during coding and theorizing was that the users of the forums may have medical concerns or doubts about the treatment that they receive, worrying about the possible health implications or complications. These ideas were verified by in the dataset. What went against original beliefs was that whilst there was a myriad of negative side-effects discussed, it was never truly considered to omit the treatments due to these.

8.2.10. Alternative solutions

The online sphere has been known to be an influential venue for promoting alternative medicine, or alternative ways for healing. Internet discussion groups on medical treatments tend to offer other patients a large array of alternative methods to curing their problem, many of which may or may not be in the best interest of the patients, since it is not controlled information from a medical expert (Falyuna, 2018).

These proposed answers can either be some sort of complementary solution (1), or in more extreme cases they can aim to replace all forms of medical treatment (2). As

suspected alternative medicine and alternative solutions were also a very influential topic in the analysed Hungarian discussion communities. As the results show, these remedies were mostly recommended when the traditional methods have failed already, at an attempt at giving hope for the others.

In the medically assisted reproduction discussion, the first type of solution (1-complementary) was observable to most extent. Only a handful of posts were about leaving the medical process altogether, and these decisions were embedded in much sorrow and disappointment (2). Either the treatment was repeatedly unsuccessful, or there was an extremely negative experience with the treating specialist.

Thus, for the most part it can be said that alternative solutions were intended to supplement the medical treatments, to “give the body a little boost”.

‘well now I put everything up for grabs, acupuncture is my last and only hope. The woman asked for six months patience, two have already passed. I have confidence, I looked for a foot masseur as well, but could not find a specialist.’ [online trace H576]

‘I read today that in they use balneotherapy for infertility successfully in Hungary, and it can be good for inflammation, closure of the fallopian tubes, scarring due to endometriosis and hormonal problems as well. I think they have a three week cure in Harkány with a professional wellness centre built for treatments. Have you heard of this? Does anybody have any experience? [online trace H217]

‘drink mistletoe tea for six weeks before transfer to strengthen the walls of the uterus. Also try royal jelly I heard it is good’ [online trace H819]

‘Get it from the herb-man from Bükk. I saw some sort of documentary and it said that they already started using the teas from uncle Szabó Gyuri at the clinic in Debrecen’ [online trace H809]

Most common is that patients referring other patients after hearing about a special cure somewhere (doctor, friend, read it somewhere). Most of these remedies are harmless as being natural, but it may not be in the best interest of the participants to try methods that are not recommended by their doctor and should keep it in mind that the advice was not from a licensed professional. Typical application situations and solutions are illustrated in detail above. Overall, the main sentiment of all these conversations is that their authors are willing to try anything in order to succeed and become a mother.

8.2.11. Personal relationships

When looking at discussions on personal relationships, three important conversation clusters were identified and subsequently analysed. These entailed (1) reactions from male partners; (2) family and close friendships and (3) network environment including for example colleagues. The first point is described separately as gendered genetic responsibility and its appearance in Hungarian infertility patients is a separate research question of the thesis. Discussion of the latter two are introduced below.

8.2.11.1. *Family and friends – the close circle*

Looking at other relationships surrounding the couple again we can see that women were asked more about when they were going to become pregnant. Accounts showed that this often felt like an inquisition for them, and secrecy was their response. Some authors talked about how their families and friends questioned their past decisions of postponement (mainly women for choosing to advance in their careers before family formation) – evoking the earlier introduced guilt narrative from the patients (the stigmatizing and isolating effect of this was introduced in Chapter 8.2.2., while the theoretical background was laid out earlier in Chapter 3.4.).

Most reports on the matter showed that couples did not inform their families about their plans, many only talked about assisted reproduction once they had already started the treatment cycle. Even then some felt stigmatized, and this added to the already stressful situation.

‘yes, you are right, I should do that. I must get myself together and continue on fighting. But it would be easier if my husband and my family would stand by me, and not always pestering me to stop all the whining’ [online trace C1129]

On the other hand, most authors said that while in treatment their family was supportive, showing empathy and compassion especially when the treatments were unsuccessful, and the couple was experiencing grief and pain.

‘we told the family right away as soon as we decided what our goal was. They suffered through the two cycles with us...there was no problem with my husband’s family either, my mother-in-law was supportive from the first moment, always asking about how things were going’ [online trace C1006]

An interesting finding in the sample is that once patients decide to confide in their surroundings, they are confronted with the fact that many are in the same shoes, and

actually have first-hand experience about what they are going through.

8.2.11.2. Network environment

It is no surprise that patients confided less in their looser network about their infertility and assisted reproduction. Especially in smaller communities, villages the childless are stigmatized. While it has been argued that involuntary childlessness is met with empathy and reported public attitudes towards medically assisted reproduction is accepting (Szalma, 2021b; Závecz, 2017), individual opinions can differ based on age, gender, education, and religiosity. Thus, most couples are bent on keeping treatment information to themselves.

It was mentioned earlier in the dissertation that women felt helplessly jealous when colleagues (especially younger ones) announced their pregnancies, and they were “forced” to watch them for months. This harbours negative emotions and can further contribute to isolation and alienation as shown in trace below:

‘Well I came clean and decided not to keep the secret any longer from my contacts, because I really had enough of everyone always pestering us why we did not have a kid already. And how come? Do you not want to be parents? And at my job (I had recently just started) I could not ask for time off for a few days (I could not go on vacation during my trial period), so I had to come clean’ [online trace C1026]

Only recently have political actors and media contributors started dealing publicly with infertility related childlessness to greater extent. Before, childlessness was mainly presented from a population-problem standpoint and not a more empathetic, supportive one. In the long-term the normalization of talking about medically assisted reproduction freely, without stigmatization may lead to more openness from and towards those personally participating in treatments.

8.2.12. Social, moral, and ethical dilemmas

While the moral and ethical concerns only appeared marginally in online discussions, when using the active method of interviews significantly more information was gathered. Lack of resources and its connection to gamete donation was one of those discussed topics that had focuses outside of the group, outside of individual interests

making abstractions through the inequalities of others in one specific thread.

'About the selling of eggs I also my opinion, but I can not condemn anyone. Who knows what will bring them to sell. Maybe there is huge Swiss franc loans, etc.. You may have to provide for children they already have, I do not know. But the fact is not nice. When I go to give blood, you do not think about how much can I get for it. I can not compare, but I did not get another' [online trace F99]

'We don't have enough money to buy, but it would be against my convictions to live off of someone's misery' [online trace F84]

As elucidated, there is a conversation between two patients, of which one needs donated oocyte to conceive, but feels that this is not in line with her moral (and financial) standing. Both agree though that once should not be ashamed of selling eggs. Support of this does not come only from a moral, but a financial perspective – they acknowledge that tough decisions are needed to be made when one finds themselves in a bad financial situation. As it was analysed earlier the material dimension of the conversation is very visible, the financial aspects are a saliently represented theme in the dataset.

When investigating the theme with the other qualitative method, the patient interviews the actively posed questions can shed light on more aspects of the topic. Based on the analysis of the interview data, the sacrifices do not only appear on the material level, but as Vicsek, Bauer and Szolnoki (2019) and Vicsek, Sándor and Bauer (2021) have shown, ethical and moral dilemmas concerning spare embryos were neglected or softened to unshackle them from these complex concerns so they can concentrate on the one main goal, to have a healthy baby. Although our main conclusion can still be that these types of concerns are not at the top of mind of infertility patients still when probed they will form opinions on the complex questions including vitrification, spare embryos, pregnancy reduction when too many embryos have hatched.

As the interviews show, there is awareness of the ethical and moral implications of the technologies, and when asked about them women discuss the issues (for more detail see Vicsek, Bauer and Szolnoki, 2019), but in their organic group conversations these complex questions are not at the forefront of debate. Our interviews focused foremost on the moral status of the embryo (namely spare embryos), and the main finding were that while the patients were aware of the ethical dilemmas, ethical and moral reasonings mainly about embryo vitrification were overridden by their desire to conceive a child, and to achieve this goal, the ethical boundaries were negotiated on a more practical level.

Access to medically assisted reproduction for gay and lesbian couples were also not amongst the topics registered in the small scale netnography (but they were issues in the large scale netnography, and Szalma's 2021 works also point out that women do form an ambiguous opinion about the issue, and this opinion is influenced by age and educational level of the participant).

8.2.13. Interpretations of time

Representations and interpretations of time in the conversation is manifold, and very much dependent on where the patient is in the treatment pathway. In most of the cases time has a negative connotation. The unveiled interpretations are the following: (1) running out of time to conceive – time interpreted in connection to aging; (2) waiting periods, waiting lists in the Hungarian health care system; (3) waiting times within the treatment cycles; (4) waiting times between treatments.

The first interpretation is a challenge on both a personal and societal level. Hungary being a traditional and pronatalist society puts pressure on women to have children and have them at the appropriate time.

'unfortunately I can't turn back time, this is a fact that I will be 38 and I still want to have a child' [online trace C516]

In the conversations this comes up connected to lost opportunities, difficulties of finding the right partner and building a career before childbearing. We can observe the guilt narrative connected to childlessness, many accounts of remorse for "wasting their time" (Detailed in Chapter 8.2.2.).

This running out of time topic is directly linked to the second time-interpretation of the theme dealing with the long waiting periods for infertility treatments. Here we witness inner dilemmas and financial struggles, when discussing how long to get the treatment in the state or private funded facilities or treatment options. This struggle is detailed above in the subchapter discussing material concerns (Chapter 8.2.8), at this point I only wish to highlight the waiting list's connection to running out of time for possible conception as follows:

'I think there is no wait list in the private funding. If you are done with the tests and slap them the money they do it right away. it's a horror price, but the clock is ticking' [online trace F57]

The third time topic concerns those days where the patients must wait for their results, for a progression in the treatment. These times are possible the most intense moments of the treatments, when they do not know what will happen or if they will be successful. One of the most excruciating periods discussed by the patients is after the transfer of the sperm or embryo, to see if the procedure was successful or they must try again.

'It is unbelievable for me that we count the passing of time in 2 week cycles. Two weeks from the start to the egg retrieval, then few days for transfer, then two weeks again waiting for the results. And now again. The days are counting down pretty well, but it is like this every time, and the end time just seems to stand still' [online trace C1266]

The most ambiguous interpretation of time is the fourth category created for waiting between treatments. While some see it as “loosing time”, others perceive this period as an opportunity to rejuvenate their bodies and souls for the next step. Common metaphor for this time is comparing this time to a vacation, as does author of online trace C641: *'The important thing is that this month has no consequences. its summer, we let the body rest and go at it again in a few months'*. It does have to be indicated that most common in the theme is the frustration of not moving forward towards the goal of motherhood.

8.3. Lay expertise and its role in the experience of assisted reproduction

As it has been established earlier, information seeking, and accumulation of medical and contextual knowledge is one of the main functions of the online discussion communities. (This finding resonates with those of Tannis (2008), and Nettleton et. al. (2005).

In this chapter, guided by the aim is to compile answers to second research question (RQ2: *How does accumulated knowledge, having contextual lay expertise influence experiences of medically assisted reproduction?*) I will look at the effect and utilization of this accumulated plethora of knowledge and experience and examine the empirical results in relation to the STS PUS models frameworks, concentrating on lay expertise, it's appearance, connotations and observed effects.

8.3.1. The findings about lay expertise

An overwhelming part, over 90% of the analysed online traces have some reference to medical knowledge and experience. Obviously, the depth of these is not unified, there are several levels from just inquiring, to having built up and utilizing the knowledge throughout their treatment processes.

Based on the small-scale netnography, 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.

As we can see that knowledge gathering either supports them to understand 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. In these instances, it is either a way to cope by projecting anger onto the professionals or institutionalized medicine, or looking for a last chance at alternatives, not willing to give up yet.

The shared sources founding this knowledge is built on is also of interest to us. 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. Although not part of this thesis, it would be interesting to see in the forthcoming time, if the disinformation about the link between infertility and Covid-19 vaccines have grounded themselves within the assisted reproduction discussions (Bauer and Koltai, 2021).

The results from the interviews showed a different picture regarding lay expertise. Whilst the patients mentioned looking up information or asking around about the experience-based knowledge from acquaintances, when being asked to describe certain medical procedures involving the creation and developing of embryos their answers were often inaccurate, there were some misunderstood procedures, and the phrases used were at times not precise.

This difference in results underpins earlier results of Tanis (2008) and Nettleton et. al. (2005), who argued that online discussion groups went beyond merely giving emotional support and have a significant role in knowledge transfer about certain conditions. Interview participants (without being specifically asked) mentioned that when seeking out information they see the online communities as an important starting point for this. Their answers underline the earlier enumerated reasons for knowledge seeking, and in their accounts, it is directly highlighted that they need to resort to information sources outside of medical professionals, because they do not have the time, or want to make the effort to engage in thorough educating of the patients about their conditions.

Overall, 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 investigated (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.

The type of transmitted knowledge was manifold. It ranges from statistical data about procedures success rate and exact interpretation of the statistical figures used in bloodwork to sociologically more complex contextual knowledge. This type of knowledge could be seen in posts discussing potential side-effects of treatments as well as comments regarding the whole treatment process. While there were negative side-effects discussed, but it was never considered to omit the treatments due to these. It is quite known that the hormonal stimulation involved with artificial insemination and other assisted reproductive technologies can potentially have significant emotional and physical tolls on the patients (Meniru, 2009), yet these descriptive statistics of potential side effects “come to life” within the online discussion communities, as follows:

‘I could literally hardly stand up, I was so dizzy all the time, and my veins hurt and felt that I was haemorrhaging all the time. I was afraid of getting cancer from all the hormones, but still, this is the way, the only way’[online trace F16]

The contextual knowledge, or knowledge through experience gained by the research subjects in several cases proved to be more trustworthy and viable to their peers than when it was just explained by the professionals. This result supports the claims of Wynne (1995, 2008) that the peers trust each other’s “expertise” to greater extent at times than textbook knowledge since this type of information is “medicine experienced as a person”, rather than just a body of facts. This type of knowledge or “lay expertise” not only addresses and accesses the medical side of the information but also integrates the physical and emotional experiences of infertility treatment. This making them archetypical lay experts. The notion of lay expertise in the study is interpreted based on the topics and tones of the texts dealing with information gathering and knowledge dissemination, and those online traces that focus on the relationship-patient relationship.

Contextual knowledge and the accumulation and mobilization of lay expertise has the following characteristics and reasonings identified based on the analysis. Participants see and evaluate their experiences as special knowledge, over 90% of the analysed online traces were about direct personal experiences. Authors, especially those who have already had extensive involvement with treatments explicitly state that their background raises the validity of their knowledge.

In instances participants state that since they have first-hand experience of the treatment processes, they know different things and at times more than the medical professionals, making them suited to give advice to others. This contextual experience is highlighted in cases where the cause of infertility is not a gynaecological issue, but an endocrinological problem.

An interesting aspect of lay expertise arises as gender comes into the focus of interpretation. As most of the infertility specialists are men, experience and contextual knowledge-based peer advice become increasingly valid coming from fellow women patients, instead of male professionals. Participants of the discussion communities 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 noteworthy, that the participants might even trust the information received from fellow forum users more than they do the information given by the doctors. Such shift in trust is detailed in Chapters 3 and 4 of the dissertation. The below verbatim illustrate how the online discussion communities serve as more than just support groups, they are a place where patients disseminate knowledge amongst each other, where they can ask the questions that there is no time to ask, or they feel they cannot ask during the visit because of lack of time, or the physicians poor patient skills. As the online sphere becomes a solid and ever-present source for information the attributed value to both the sources, and the distributed answer escalates (at times without any real verification.)

'Yes, I already know that from the forum.' [online trace F04]

'It is a bit sketchy that I have gathering more info from the forum than the doctors.'
[online trace F29]

'Until then we are here for each other as information sources. What would happen to me without Internet...' [online trace F68]

In some cases, the accumulation of lay expertise can have significant impact on the dynamics between professional and patient throughout the infertility treatment pathway. The traditional paternalistic relationship is questioned by the patients through their acquired information and contextual knowledge – thus we can state that the disseminated knowledge has an offline afterlife. Patients report that they are much more likely to pose questions, expect explanations or have a preference of the way treatment should happen. While this distinguished e-patient knowledge is higher than the average, it does not

surpass the professionals, yet based on their experiences and lay expertise, the asymmetric communication style can be challenged. When their will for a more symmetric communication style is not met, the knowledgeable patients get critical, and they are convinced that these criticisms are based not solely on emotions (this change in the doctor-patient relationship will be explored in greater detail in the subsequent chapter of the dissertation). This type of reliance on their own acquired knowledge to verify expert opinions is summed up in the following patient comment: *‘its really difficult for me to straw through all the doctors’ opinions to find out what is actually good for me’* [online trace F78]. The statement shows how lay experts view their knowledge as being on the same level as professionals’ advice.

The perceptions of the lay expert patients are that they are capable of formulating criticisms not only about the circumstances surrounding their treatments but in addition about the medical and technological methods and the competency of the doctors. As a result, these patients are more and more likely to demand to be listened to during the determination and process of their treatments. If the information-flow, the more symmetrical communication design, and the will to be more engaged in their treatments are failed to be met, it fuels the already decreasing level of trust in both institutions and doctors. While the more involving communication, and a more mutual respect-based doctor-patient relationship may be beneficial to the practice in long-term treatment cooperation, the loss of trust and turning away from the system can significantly hinder the processes.

8.3.2. Discussion on lay expertise in medically assisted reproduction treatment experiences

8.3.2.1. Concise answer to research question

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

The results show that knowledge has a definite impact on the patients’ experience of the medically assisted reproduction process. The thesis does not focus on the actual, measurable knowledge gap between professionals and their patients (as the research

approach turns away from the traditionally used and highly popular deficit-model and relies on an interpretative and constructionist approach to understanding lay scientific knowledge) but looks at the motivations and consequences of the accumulated knowledge, which have proved to be assorted.

This influence is manifold, for some it provides confidence, to be able to follow and understand their treatments, their knowledge allows them for feelings of validation. Knowing more about the process grounds them, giving them, some leverage in the turmoil of treatments and the health care system. On the other hand, lay expertise can also have the negative consequence on compliance, if the patient relies on her lay knowledge not as complementary, but as substitution to verified medical protocols, and turning towards purely alternative solutions.

8.3.2.2. Detailed discussion on lay expertise in medically assisted reproduction treatment experiences

In context of the theoretical framework of the thesis, we can observe that the constructivist approach has highlighted the importance of experience-based knowledge and demonstrating the appearance of lay expertise in the infertility patients' community. This type of knowledge interpretation differs in its core from the deficit model detailed in Chapter 3.2.3.1. of the dissertation, the model that had guided STS inquiry alone during the first section of its brief history.

As we could see in the theoretical literature review the concept of lay expertise is a controversial one, there is debate about its existence, and the ability of researchers to properly identify lay expertise.

In my attempt at linking existing theory and research results, I found that 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. Using the lay expertise PUS model proved beneficial in the research because the knowledge and the attitudes of patients cannot be understood by studying the evident scientific knowledge gap alone, in this sense the thesis contributed to the plethora of knowledge of public understandings of science, especially to the strand of PUS thinking initially introduced by seminal works of Brian Wynne (1991, 1992, 1996). The concepts linking science and

the layman, the public understanding of science models, with the emphasis on the introduction of lay expertise can be found in Chapter 3.2.3 of the dissertation. The subsequent part of this chapter discusses the interpretation of lay expertise.

The literature showed that for a long time the everyday experiences of patients encountering innovative scientific technology have been for the most part set aside (while the deficit model was dominant, the knowledge and information gap was the focal point of research (Bucchi, 1998; 2013; Wynne, 1992)), only later have new concepts in PUS research have emerged – detailed in Chapters 3.2.3.1. and 3.2.3.2. of the thesis. It was not until the introduction of the contextual model (Brossard and Lewenstein, 2010) that the individual and social aspects of the encountering public were taken into consideration at all.

The lay expertise and the public engagement models have built on these above tenets and underline similar public attitudes, knowledges, and dispositions that we have encountered during our analysis. Thus, the thesis research has provided additional empirical support for theoretical concepts in the field of science and technology studies.

Wynne has from the start of his research in the field considered these forms of lay knowledge inherently supplementary, with deeply rooted personal motivations for its acquisition. This claim has been supported by present research, which has demonstrated both the depth of the patients' knowledge and the considerable time and effort the sampled patients have spent accumulating it.

As Lambert and Rose (1996) put it, infertility treatment, and assisted reproduction are fruitful grounds for building lay expertise because of the length and nature of the treatments, and this was supported by present research. The netnographic analysis of the texts show that, many of the participants can be considered deeply knowledgeable and seem to possess a wide range of information on the processes – having accumulated both concrete medical knowledge (through their research and online communication networks) and contextual experience-based knowledge from participating in the treatment cycles.

I feel it is also important to address the question if the observed knowledge can be classified as lay expertise. To engage in the debate of those sceptical towards lay expertise (Prior, 2003 or Collins and Evans, 2002) I rely on the enumerated arguments of Myskja (2007) regarding its definition and components. On the following pages I aim to underline

how the patients' accumulated knowledge that has been investigated in the thesis research and presented in the doctoral dissertation meet the criteria of lay expertise⁵².

Arguments from Myskja (2007)	Evidence presented by research findings
<i>“Lay people who are educated into quasi-experts on a particular issue or technology”</i>	The results from the netnographic analysis showed the effort from the patients to become and stay continuously highly informed about their conditions and the specific technological solution they encountered.
<i>“Lay people who turn themselves into experts in order to challenge scientific experts”</i>	When investigating the question, we found that the main motivations for knowledge accumulation is either to gain validation or to confront the treatment recommended by the medical expert. ⁵³
<i>“Lay people with particular knowledge based on tradition and experience”</i>	The expertise in this research is partially rooted in experiences gained throughout the infertility treatment paths. Tradition in our case played a lesser, only contextual role as the research was conducted in pronatalist society with a traditional view on the significance of biologically related children.
<i>“Lay people who represent an alternative perspective to expert views because they are non-experts”</i>	The analysis of the online conversations showed that some participants valued the information they gained from the forum more, than that obtained from medical

⁵² The debate on lay expertise and the utilization of lay knowledge is detailed in 3.2.3.2. chapter of the dissertation.

⁵³ The effect of this motivation on the doctor-patient relationship will be detailed in the next chapter of the analysis.

	professionals, exactly because they did not rely on text-book 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 the female bodily experiences.
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Adding to the second point of the above, Arskey (1994) and Epstein (1996) argued that with through the specific lay expertise disposition the patients can become an archetype of watchdog of science. Although this notion was not explicitly observed in the results of the research – as there were no patient groups formed to advocate policy changes, implicitly the members of the community adapted this function, while utilizing their knowledge to evaluate and validate the treatment offered to their peers.

As Barker and Galardi (2011) posit that since lay expertise partially stems from personal experience, its disposition is never neutral. Thus, during our interpretation, we must also take into consideration the problems that can be caused by this self-evaluated, self-determined expert type. Moreover, as Rózsa (2016) and Molnár et al. (2018) argue, that such active participation and change in perspective is at the core of modern patient behaviour, having considerable influence on the doctor-patient relationship.

Their claims are also supported by ideas of Nichols (2019), who argues that emotionally charged, false claims feelings of symmetry between verified knowledge of the professionals, and the experience and emotionally contingent knowledge of lay expert, e-patients can in extreme cases be dangerous both for the relationship and proper compliance. The mechanisms and consequences of this mobilization of lay expertise affected the relationship between the doctors and patients is explored in the subsequent chapter of the dissertation.

8.3.3. Public understanding of science, lay expertise and the implications for further research

The design of large scale netnography has been prepared by the author of the thesis to see how the other PUS models can be utilized in the research for a holistic study of public perceptions of medically assisted reproduction in the Hungarian open web discussions. This topic of inquiry should also be investigated with the use of other methodologies that focus on active methods and offline data.

In addition, the lay expertise model may prove for a fruitful model for researching other medical conditions, a novelty being Covid-19, examining how long-hauler coronavirus patients' expertise emerges and influences their care.

While adapting the lay expertise model for understanding experiences of infertility patients, further research using other PUS model, the public engagement model could be fruitful, as the nationalisation of infertility clinics, and limiting access to assisted reproduction may lead to the formation of patients' interest groups. Recently this type of public engagement, reaching their goals in influencing policy from groups of Sinopharm vaccinated people may provide an example⁵⁴.

⁵⁴ The author of this thesis is investigating the online roots of these patient groups and aims to publish research results in 2022. The results of the large-scale netnography were not added to the dissertation, a decision that was made with practical considerations in mind. Limitations of the thesis format would not allow for full detailed examination, and the comparison is thus more suited for stand-alone publication. In addition, the author of the thesis has found co-operators to include from the field of social psychology enabling the final project to become interdisciplinary.

8.4. Representations of the doctor-patient relationship

The subsequent chapter looks at how the doctor-patient relationship is interpreted by the patients, providing results to the third research question brought forth in the dissertation (RQ3: *How is the doctor-patient relationship represented and presented in the conversations?*).

As it was illustrated in the prior section dissecting the research questions dealing with knowledge, lay expertise can be and is often mobilized to influence the doctor-patient relationship. This part of the thesis expands on this finding, in addition introduces other aspects influencing the dynamics of the doctor patient dyad, connecting the research results with theoretical models of the doctor-patient relationship and selected concepts of biopolitics and biopower in the medical setting.

8.4.1. The findings about the doctor-patient relationship

One of the main themes identified during the netnography contained conversations about the medical professionals, and how the patients viewed 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, distinction was made between the intent and the knowledge of the medical professionals.

As medically assisted reproduction is quite a long-term and emotionally and physically volatile process, the patients' opinions were expressed in great detail and unfettered by constraints, so the language was not always calm. The most extreme of accounts were those of blame, the intent and 'humane behaviour' was questioned, and medical professionals were characterized as devoid of emotions and compassion. These points will be explained in greater detail on the following pages.

Relationship with the medical professionals was also an important topic that emerged through the analysis of the patient interviews. 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.

Comparable stories of multiple failures and disappointments emerged (both the netnography and the interviews depicted similar patient treatment pathway models), but the negative experiences were not associated with false claims from the specialist, negative intent was not emphasized. Even during the qualitative interviews, when the question of money came up (which was a huge tension point identified via the netnography), the interview participants showed restraint in tonality and face-to-face portrayed disposition.

Despite the dissimilarities identified (partly due to the diverging nature of the passive and active methodologies), an essential element was reinforced by the interview analyses, namely that patients were unsatisfied with the asymmetric nature of the relationship, both with regards to the flow of information and the bedside manners of the medical staff.

Another critical issue that was unveiled thanks to the multi-method approach, is that ethical and moral issues are not in the focus for patients. (This reinforces the findings of Vicsek and Gergely (2011) and, Vicsek and Bauer (2012) arguing that there is no relevant public debate in Hungary regarding biotechnical innovations and morally complex technologies). Organically these questions had exceedingly small presence in online conversations, and answers to them came from the patient interviews. The reason for examining the theme here is because one of the reasons behind the absence of thinking about such questions lays within the nature of doctor-patient communication about these dilemmas, or as we could see in our case the lack of discussing them.

Relying on the approach of thematic analysis, several topics of discussion were identified homing in on the doctor-patient relationship. To reiterate there were four main forces and mechanisms identified in the theoretical literature that heavily influenced the dynamics of the doctor patient relationship, evolving from an asymmetric, hierarchical set of roles to the emergence of a more consumerism based cooperative relationship (Cavenagh et al., 2013; Cockerham, 2021; Fair, 2010; Rózsa, 2016, Molnár et al. 2018;

Vanderminden and Potter, 2010). The overall Hungarian mentality is showing increased criticism towards the health care system and the professionals working in it, so this devaluation of doctors' authority is not only unique to assisted reproduction, but because of the nature and the practice of the treatments it can escalate and be exposed easier.

Enumerated the points are the following: (1) closing of information gap; (2) lay expertise; (3) limited trust towards medical professionals; (4) consumer attitude of the patients. Empirical manifestations for these could be found in the analysed samples of patient narratives, and these will be presented on the following pages.

The information gap's closing has largely to do with the readily available, online open-source information on medical topics (and thus the way patients have the agency and ability to access and interact with them in the online sphere). Explicit references to open access information sites were made quite often, the communicators expressed at length how and where they access medical information online, and how the learned details and facts influence their attitudes towards treatments and the healthcare system. It is not within the scope of the present study to analyse the validity and reliability of this gathered medical knowledge, merely to state its effect on the role which patients assigned themselves when coming into contact and communication with medical professionals. 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.

The incorporated knowledge can build a stable background, so that the process of treatment can be constructed together, but ultimately driven by the professional. It can also build cooperation with creating effective, more equalized communication, based on regular Q&A between professional and patient – adopting a patient-centric approach to the doctor-patient dyadic interactions.

In the middle of the range between cooperation creating and diminishing trust the category of 'searching for complementary treatments' can be found. This type of patient

attitude does not take away the authority of the doctor entirely (a basic asymmetry stays grounded in the professionals' medical knowledge and expertise) but does partly question the success of the recommended treatment.

At the other end of the spectrum, we can see how the gathered information and accumulated contextual, lay expertise can be a tool to question medical authority, as is explicitly discussed by the author of online trace, F98: *'I soon won't believe in any doctor anymore, 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.'* Using the information sought out in peer groups, the validate medical diagnosis is another form of questioning authority, while opting out of treatment and choosing an alternative medical solution, is a form of permanent exit from the doctor-patient dyadic relationship.

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. Once trust has broken through an unpleasant experience, as the accounts show us is extremely hard to re-establish, not only towards the practicing individual professional, but the entire system. *'That doctor ruined me, I am never trusting them again. I told them what needed to be done, but of course they did not listen to me... So this is the situation everywhere, I mean they rip you off with money! It's good business for them, and it is not worthwhile for them to make everyone successful on the first try!'* The extremely negative experience portrayed by the author of online trace F09 shows just how fragile and vulnerable the relationship is. And how dire the consequences can be when the trust is broken. Although the cited story exemplifies an extreme reaction, there are many authors who have exhibited more subtle and complexly nuanced distrusting behaviour towards the medical professionals. An example of the consequences of such mistrust is that the patients start arranging aspects of their treatment themselves without advice and supervision of their doctors. One author, who decided to take this route reported doing so after severe disappointment:

'Unfortunately the fourth transfer was unsuccessful again...I am totally out of it, I have never felt this bad, I am heartbroken, because I do not know what I should do about the tests, most of them I arranged myself and had them done independently' [online trace C1330]

While the above phenomenon is directly stemming from a negative experience,

another of the identified mechanisms behind the changing doctor-patient relationship is also identifiable. Overall, the growing consumerist attitude can be observed (also resonating literature introduced in Chapter 3.3). In addition, expectations of the consumer infertility patient are especially high due to the hybrid practice of state-funded and private clinics, or treatments⁵⁵.

On the one hand, 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. This patient expectation is detailed in the following account published in an online comment:

'That is why I was so nervous and it felt bad for me, because I saw that all the other girls had their doctors by them, they comforted them, told them that everything is okay. And my doctor, I don't want to hurt him, he may have a lot of patients, but he never came over. ... It was a really bad experience, we were waiting there for someone to come in finally. It was really uncomfortable and I had no idea if I was allowed to move or anything. And he never came over.' [online trace F215]

Again, here it must be stressed that the disappointments, and failures can be projected onto the professionals, creating a much more negative online imprint of them. Thus, the above detailed unpleasant experience also has to be viewed through a lens of objective caution.

Beside 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. As argued earlier the online traces reveal a difference of patient attitudes towards the assumed knowledge and the believed intent of the doctors. Doubt in knowledge was less significant (the authors focused at greater length on the motives behind behaviour) and discussion mainly entailed that there are special fields that the professionals have less or no experience with and thus the rate of misdiagnosis among the infertile women is rather high (this was especially expressed that the gynaecologists have limited knowledge of diagnosis and treatment of

⁵⁵ At the time of the data gathering the regulation for the nationalization of infertility clinics have not yet been implemented, there was still opportunity to have care in a private owned facility.

endocrinological malfunctions), as seen in account I29: *‘these doctors know nothing about IR, but they will not admit it’* [online trace I29].

The question on the intent and this type of speculated misconduct was discussed in greater detail than the aforementioned gaps in knowledge or experience. Intent in these accounts had more to do with lack of caring or the personal affiliation and desired career advancement (having a good statistical success rate both for themselves and their clinic), than medical expertise of the professional. Several posts depicted doctors simply not caring about the patient, not treating them as a human being, just a case that must be solved, when for instance an IVF cycle may need extra attention from the medical professional.

An important portion of the discussion went even beyond this and questioned the ulterior motives of the professionals. Stories were devoted to detailing how the intentions of the physicians are primarily not to help those couples in need, but merely to make a profit or stabilize their success-rates. A detailed introduction of such patient perception can be read in an online account:

‘the answer from your doctor, well unfortunately it is true that nobody likes the problemed patients with only slim chances (or at least I think only a few might) since these cases ruin their success-rates, It is easier to blame the patient and tell them they should have made up their minds sooner. In my own profession I also start something with less enthusiasm if I know there will be no business in the end’ [online trace F29].

As elucidated above extreme disappointment, and even hatred was expressed towards doctors who in their view do not take the interest of patients in first place but only „go for the money”. Often, they feel used and capitalized on for the financial benefit of the doctors. There were posts that mentioned the professionals deemed unqualified by name and location of practice. This served a purpose of warning for those patients who were thinking of looking that physician up⁵⁶. One specialist was mentioned with greater frequency in an extremely negative context:

*‘He didn’t give a damn about me, wanted to be over so he just got rid of me.’ ‘Yes it was Dr. ***. I too felt totally betrayed.’* [online trace H994].

Naturally not only the negative aspect of healthcare was discussed, a few doctors,

⁵⁶ The names of both the professionals and the clinics were edited out of the verbatim by the author of the dissertation.

specialists were mentioned with praise and respect.

'It was a good experience. They were very empathetic, and you could hear it in their voices that they were happy when they told you the good news, and that they are very pretty and you could hear their joy.' [patient interview D04].

'they explained everything to me, I could ask all the questions I wanted, But you must know that this was a fully private clinic, no state funding. they did all the tests there, everything I asked for.' [online trace C91].

But overall, it can be said that compared to the negative messages the type of positive sentiments portrayed above were significantly less in salience – this is in line with what was discussed in Chapter 8.1.2., where the negative tendencies of the online sphere were detailed, which lead to there being less space for positive comments than in patient interviews.

8.4.2. Discussion on the role of changing doctor-patient relationship in medically assisted reproduction treatments

8.4.2.1. Concise answer to research question

RQ3: *How is the doctor-patient relationship represented and presented in the patient accounts?*

We can identify a hierarchical tension in the relationship of the doctor-patient dyad. While patients feel that they are owed autonomy, and adequate information, moving away from the traditional Parsonian sick-role and adapting a modern consumerist patient character (much more in line with the more recent and modern Mead-Bower model (2000)) of doctor-patient relationship. In their accounts the doctors prefer, behave, and communicate according to the more traditional interpretation. The mentioned tension is expressed in emotional accounts, questioning the knowledge and intent of the medical professionals.

8.4.4.2. Detailed discussion on the role of changing doctor-patient relationship in medically assisted reproduction treatments

The analysis clearly shows that there is an underlying tension within the doctor-patient dyad (especially when the patients are participating in the private financed treatments or care). If we look at the models introduced in the medical sociology

theoretical literature review (Chapters 3.3.1. and 3.3.2.), we see a clear distancing from the Parsonian sick-role theory in the patients' accounts.

As outlined earlier, the Parsonian-model (1951) assigns certain obligations and privileges – aka, roles to the patients and the professionals. The structure of these roles in Parsons's view was highly asymmetrical and hierarchical. As we observed in the dataset of the investigation, the obligation refuted by the patients the most vehemently was the unquestioned cooperation with the physician. This in turn, also leads to countering one of the main rights of the professional role, namely that they solely occupy the position of authority (they maintain sole prerogative in assigning the sick-role to patients in addition to formulating and prescribing the only 'suitable and adequate' treatment) in the dyad.

The Parsonian-model does not allow for the type of communicating, negotiating and mutual decision making that is acceptable to today's more knowledgeable and independent patients. Szasz and Hollander (1954) have coined this the "activity-passivity model", which assumes the least amount of contribution from patients. Szasz and Hollander and subsequently Mead and Bower (2000), and Hellín (2002) argue that this type of relationship infantilizes the patients and can cause significant sources of frustration for those patients, who feel the need for their experiences and opinions to be taken into respectful consideration. They are looking for a relationship that Szasz and Hollander have defined as the "mutual participation model". This type of cooperation as we could see is expected by the patients, and when their needs are not met, narratives showing off significant tension could be identified.

This is especially the case with those patients that have had many experiences and have accumulated significant knowledge and lay expertise as explained in the portion of the thesis (Chapter 8.3). 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.

While the traditional Parsonian concept bases the relationship on authority breeding from professional knowledge (and relying on the knowledge gap between

professionals and patients), the later Bower and Mead model (2000) takes a myriad of attributes and influencing factors into account. Analysis of the patients' reports have shed light on how the physicians' attitudes, styles, personality, and knowledge of the patients' specific conditions are considered especially important by them. It seems (based on the accounts in the dataset) that in such intimate treatment situations, as medically assisted reproductive treatments are the personal dispositions and emotional availability of professionals is of extra significance. The introduction of the results above has demonstrated the level of tensions and the volatility of patient frustrations are when these needs are not met.

In addition, Kaba and Sooriakumaran (2007) and Molnár et al. (2018) have also argued that seamless cooperation between the two actors can only be achieved through a patient-centred approach, otherwise the tensions in the communicative relationship will affect compliance. This is supported by our research results, especially in the case of those patients who participated in private funded treatment cycles. Thoughts of Haug (1976), Davis (2010) or Vanderminden and Potter (2010) all suggest that patient expectations rise as they identify themselves more as clients rather than assume the sick-role.

One of the main triggers of the change in patient behaviour is grounded in their accumulated knowledge. In the earlier chapter we stated based on notions of Wynne (1991, 1992, 2008) that gaining experience-based knowledge and becoming lay experts can contribute to questioning authority, and the need to flatten the hierarchical positions of the doctor-patient relationship. Findings from the research (especially the netnography prong) strongly support this claim. Knowledge is used to validate medical opinions and question authority (detailed in Chapter 8.3).

Changes in the relationship between doctor and patient can also be examined from the perspectives of biopolitics and biopower. If we look at the relationship as an expression of power relations, we can conclude based on the works of Memmi (2003, 2015) that the authority is still concentrated there, and that the medical professionals are still regulating and steering the patients away from autonomous decisions through their communication during the visits. Memmi has coined this as professional biopolitics.

This was most evident in the patient interviews, when discussing the fate of spare embryos. Pairing the findings with the theories of Memmi (2015) we can see evidence of

what was introduced as multi-vocal governance. In this model all information must be provided to the patient that allows for them to make autonomous decisions on their own (“delegated biopolitics”), but the everyday practices and conversations during visitation show that in reality, decisions are heavily influenced by the advice and prescribed practices of the medical professionals.

Based on the expert and patient interviews decisions regarding spare embryos were detailed in studies by Sándor, Vicsek and Bauer (2017), and Vicsek, Sándor and Bauer (2021), but the analysis on the dataset forming the basis of this dissertation also found evidence that patients felt that doctors were persuading them towards certain solutions, while dissuading them from others.

Firstly, they felt that doctors were pushing them towards the private funded treatments (introduced in Chapters 8.2.7, and 8.4.3), secondly, they reported that some doctors would not take on complicated cases, or patients above a certain age and tried to negotiate with the patients to stop with the treatments. Patients reasoned that this is due to them wanting to achieve better success rates. Based on their accounts this “pushing” did not happen directly or explicitly but was merely suggested and advised. Still despite its implicit nature it burdened and aggravated patients. Again, as throughout the analysis I must reiterate that patient accounts can be influenced by the anger and frustration that they feel when their procedures are not successful and elaborated ventilation about their situation and (mis)treatment can be a coping mechanism.

8.4.3. Implications for further research

In the expert interviews (used in the doctoral dissertation to add context to the study of the patients’ perspective) we marginally had the chance to observe that not all medical professionals knew how to deal with, or even wanted to engage with the new type of e-patient asserting their knowledge and questioning the physician’s authoritative position. Though the professionals’ general attitudes were not the topic of our investigation in this project, I believe that it would be beneficial to study the professionals’ reactions to the changes identified in the dyad’s relationship.

This could be indeed fruitful because over the last year and a half, during the Covid-19 pandemic further loss of authority and thus patient compliance could be observed. The strained relationship between medical staff and patients seen during the pandemic implies that new type of communication and orientation is necessary, to which the roots need to be understood through further investigation.

8.5. Gendered genetic responsibility in medically assisted reproduction

The last analytical section of the dissertation deals with the question of gendered roles and responsibilities during medically assisted reproduction. Mainly this section focuses on how the pronatalist orientations and mechanisms of society along with gendered prenatal roles of this society appear in the narrated experiences of patients.

The question of gender foremost appears in the context of the patient women reporting about their partners, so taken from the network theme the roles of partners and partnership is analysed in this section of the thesis, to go into greater detail on answering the last research question. (RQ4: *How do gender roles and gendered genetic responsibility influence the Hungarian patients' narrated experiences?*)

8.5.1. The findings about gendered reproductive burden

Thematic analysis of both the netnography and the interview datasets present results on gender roles based foremost on how the patients were discussing their relationships with their partners, detailing their participation in treatment and the attitudes they portrayed. The following pages introduce these findings.

As discussed earlier in the theoretical section, different attitudes from society are observed when viewing female and male childlessness, and infertility (the theoretical background of gendered reproductive responsibility can be read in Chapter 3.4. of the dissertation). The international and Hungarian literature (Ettore, 2002; Lindsey, 2017; Szalma, 2021a, 2021b); has highlighted that the responsibility and burden is placed foremost on women. Women are those who are perceived as socially responsible for decline in birth-rates, and it seems as they are the ones who carry the responsibility with medically assisted reproduction as well.

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. Recruiting men for interviews proved at the time impossible (detailed in methods section of the thesis), and similar barriers were reported by Szalma (2021a, 2021b), granting a salient opportunity for further future inquiry. In the analysed texts we could see that the male partners' coping mechanism discussed most was silence, not talking about the problem, bottling up the feelings.

There were participant accounts of men having different reactions than their female counterparts. From the analysed texts it seems that most of the decisions were made by the women, many because they needed to be made promptly.

Male participation in the treatments were 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 if 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. Based on the participants' stories women were much more active in the planning, the information gathering and the organising of the treatments. They were the ones mostly in charge of looking into the details of the testing, the clinics, the doctors. Women were the ones looking up the medical information and joining in the online communities to better inform themselves and based on what they learned they were the ones who set up and kept track of the appointments, tests, and procedures.

Despite being more involved and accepting more responsibility in organizing the treatments and keeping track of the procedures, the female patient accounts do not show any signs of this causing problems in the relationship, while the partner is supportive. The below online report confirms this, and also illustrates that this control is partly because the male partners are more anxious and focused:

'I looked into the doctors' and clinics' success rates and decided where we should go. My partner came when he could, but sometimes I did not want to bother him with every little detail. He was more stressed, I just did what needed to be done' [online trace F91].

Also, from the data analysis it can be derived that the emotional involvement and physical reactions experienced by the men differ greatly from those of the women. Except for those instances when the male partner needs some sort of invasive treatment, such as surgery, their involvement is less physically taxing, and does not last throughout the treatment pathway. In most accounts, the male partner needs to give a sperm sample for testing, and another sample for vitrification, insemination, IVF or ICSI. While the women report (based on their partners' accounts) that these procedures can be uncomfortable, embarrassing, or emotionally taxing, they are physically less invasive than what the female counterparts must endure. For the most part according to the accounts men do not make a big deal about these procedures, but some accounts are about bad experiences.

As mentioned earlier due to the less focal nature of male infertility patients, still limited information has been accumulated about how they react emotionally. What we can see from the female patients' reports is that one of the male partners' main concerns is over the wellbeing of their partners. They see both the physical and emotional burden women face and worry about how they are affected. This supportive attitude was registered in most of the sample, only a handful of instances were observed when the women were complaining about their partners' unsupportive behaviour.

Interestingly these instances of lack of support were in connection with two key issues: (1) material burdens; and (2) a strictly controlled, procreation-oriented sex-life.

According to the women patients' accounts, their partners were more likely to recommend giving up treatment cycles due to the financial burdens. One explanation for this could be that the traditional male-breadwinner model is still popular in the pronatalist Hungary, and the male partners are more in charge of the family budgets. Another possibility is that some women patients have given up their careers and occupations at the altar of becoming a mother with the help of medically assisted reproduction. Only in a few accounts did we register that men made these decisions because they saw their female partner to be too emotional to make such life-altering decisions.

The netnography showed that some authors felt that their partners missed the spontaneity of their earlier sex-life and had a tough time restraining themselves.

'Well during the treatment, I was just not in the mood, so before stimulation my husband had a period of self-restraint that was quite hard for him.' [online trace F69]

Reports of patients have less interest in having intercourse because of the hormone treatments were also represented in the analysed sample of online discussions.

'While we weren't allowed... Even after the transfer... So there has been nothing since February... My husband doesn't understand...' [online trace F108]

Apart from these handful of instances the authors accounted that their partners were incredibly supportive during the treatment process both emotionally and physically, when having the opportunity.

'I felt so horrible, I was weak and nauseous all day and had to rest. My husband had to do everything including the gardening) for the weekend.' [online trace F91]

'I was crying all the time from the hormones, I was a real dragon lady was once tolerated at home' [online trace F108]

They even participated quasi-medically, when the women could not inject themselves with the prescribed medication, as in case of the report from online commenter: *'We had to stick my stomach with hormones all the time.'* [online trace F22]

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.

The anxiety and negative experience of being separated during treatment also appeared in the offline interviews. A detailed description was narrated by a patient while interviewed by the author:

'they took me to another room, my husband could not be there for the transfer, we were apart and I was scared. I wished he could be there to hold my hand, I felt so alone after just laying there, spread open and exposed' [patient interview D12]

Accounts of going alone to the visits because partners did not get time off was

reported by most interviewed patients and appeared more frequently in the online data as well. Both mentioned typical situations resulted in, or highlighted the fact that the doctors and other medical staff communicated foremost with the women, who played an intermediary role because of this practice.

When analysing the data about the partners, again notions of biological kinship and the path of adoption comes into focus. From our sample, we can conclude that the importance of blood relations is extremely high, and couples say that they would rather remain childless than raise an adopted child who “*belongs to someone else and is not theirs*”, a concise presentation of typical reasoning can be found in a both an interview and an online comment fragment shown below:

‘it was an emotionally hard thing, which I never thought would happen, because we never lost hope my husband and I, but when we found out we did not tell anyone, we needed two weeks to get a grasp and define our parameters. We said no adoption, but we will try ivf and if there is no baby, then we will live without having children.’ [patient interview D17]

‘We were like we either have our own or not at all. Don’t be mad at your husband for this, it is totally normal the way he is thinking, it can’t be the end no matter how much you want a baby’ [online trace C612]

This closing off from the adoption option may originate from the sample and may not represent the Hungarian population’s general attitude towards family formation through adoption, as the women in the sample have dedicated themselves already to participating in assisted reproduction (Keresztes-Takács and Nguyen Luu, 2017).

When discussing having a baby with donated gametes, the opinions show greater range. Most did not have any problem with the process (no ethical concerns at all) and discussed it in a wishful and optimistic tone as another opportunity to have a biologically related child.

Only a handful of comments were sceptical towards having a third persons’ sperm or egg involved in their family.

There could be problems when one is at fault I think. They don’t accept the child, they don’t love it and they feel as they have missed out on something...The child would feel bad that its not her biological mother? maybe’ [online trace C985]

‘My husband would never go for it, it must be his’[online trace F61]

As exemplified above from the online female patient accounts, it was their

partners who objected more to having a sperm-donor and seemed less willing to raise “another man’s child”.

8.5.2. Discussion on gendered responsibility of the prenatal in medically assisted reproduction

8.5.3.1. Concise answers to the research questions

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

The research results support that there is an unequal distribution of reproductive and genetic responsibility between genders. 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.

8.5.3.2. Detailed discussion on gendered responsibility in reproduction and medically assisted reproduction

Locock and Alexander (2006) have argued that the male perspective is overlooked in the literature on reproduction, and unfortunately the thesis does not assist in filling this gap, as the examined sample consisted of women. While methodologically this poses a problem, at the same time it does provide answers about the gendered nature of reproductive responsibility. The fact that women assume the role of information gatherers and organizers are apparent by just viewing the composition of the sample. The online discussions were dominated by women, and at the time of the data collection there was no platform dedicated to the hosting of male conversations on medically assisted reproduction.

Hungary is a pronatalist society, this we can observe this in the way the public attitudes towards childbearing (only a very small segment of the population thinks of being childless as a good situation) and clearly in the policies and communications of the conservative government (Kapitány and Spéder, 2006; S. Molnár, 1999; Szalma, 2021a, 2021b). This attitude towards placing emphasis on biologically related children is explicitly present in our sample, reports were observed about rather not having children at all than having one that is not biologically related to at least one of the parents. It must be noted though that this finding may be skewed by our focus on patients partaking in treatment processes, so they may be more dedicated to genetically related family formation.

Several of the dimensions of pronatalist birth encouragements identified by Heitlinger (1991) appear in the narratives of childlessness and infertility spotted in the sample. To reiterate these dimensions were (1) cultural, (2) ideological, (3) psychological, (4) cohort and (5) policy. While the two latter were not saliently apparent in the patient stories, they do play an influential role in public debates about childlessness and even medically assisted reproduction.

The cultural and psychological dimensions were seen in the narratives reflecting on punishment, warrior, inadequacy, and stigmatization, while the ideological dimension was mirrored in the punishment narrative. Selective nature of pronatalism was seen in a few accounts where patients reported that their treating fertility specialist urged them not to proceed with the process, because of their conditions or age. (Patients connected this type of selection to the intent of the doctors, and this aspect was detailed in the previous chapter).

As we could see in the prenatal studies conducted by Reed (2009, 2012) women proved take on the mass of the reproductive and genetic responsibility – in the Hungarian sample of patients participating in medically assisted reproduction these findings were also supported, and some of the reasoning behind the fact showed similarities despite British and Hungarian societies being different. The main message of these investigations is that despite an overall transition trend into new type of fatherhood (Locock and Alexander, 2006; Dick, 2011), resulting in fathers who are much more involved and present during and after the prenatal period, the reproductive responsibility is still skewed towards women.

Reed (2003) mentions the fact that women show more activity when looking for information about childbearing, and prenatal. Her British result was supported by findings of our research – underlining those aspects of the traditional gender roles and division of labour in reproduction that are solidified despite the changing trends. In addition, the literature also supports that women are in fact more prone to look for and collect information on health issues in general, and they bear the responsibility for health in the family (Markens, Browner and Preloran, 2003). On the other hand, Locock and Alexander (2006) argue that men were effective in gathering medical and technical information, albeit not being actively involved in discussion support communities. The authors refer to this form of male participation as “gatherer and guardian of fact” and link it directly to the new type of fatherhood involvement. The results of the thesis research did not support Locock and Alexander’s findings, we observed that the new type of fatherhood did have manifestations in the form of presence, but not in connection with information gathering.

The disposition of the medical staff also adds to these differences observed in taking responsibility. According to our findings we can conclude that during medically assisted reproduction the women are considered the primary contact points, the main receivers of disseminated information from the medical professionals (concurring results of Reed (2009; 2012) – thus they become to use the terminology of Reed (2012) the “gate-keepers of information”.

According to Ettore (2002) women’s bodies are ranked based on their “genetic capital”, their “breeding potential”. In this sense they are the ones who are designated as guardians of the foetus. Our research shows that this is definitely the case, women become the protectors, but as shown in the subchapter discussing the feelings of motherhood (Chapter 8.2.3) this happens instinctively or on a subconscious level.

Vicsek and team’s works (2016, 2017, 2019) show that these processes are murky, and the way the medical staff communicates at the clinics influences the patients’ dispositions greatly (this concept of governing through speech, and professional biopolitics was introduced earlier through the works of Memmi (2003, 2015)).

We have noted that the attitudes and practices in medically assisted reproduction in Hungary point to solidifying the traditional gender roles. While this may be the consequence of practice, from patient accounts we can observe that in several cases this

is not the intent of the patients. The male partners wish to actively participate and share the reproductive and genetic responsibility, but the routines and rituals at the fertility facilities, or their role in the traditional male breadwinner family formation prevent them from doing so.

In the detailed description of the results, we could see that the men were often not let into certain places in the clinics where the procedures were happening, or the visits were scheduled during the daytime, and they had difficulty leaving their work. This was emphasized as problems in the system by the participants, who reported that missing these moments caused stress and negative emotions for their partners. Thus, from our findings (to some extent supporting earlier findings of Reed (2009, 2012)), we can conclude that placing the burden of genetic responsibility on women is not the intent of the partner (micro-level) but originates from the way society looks at prenatal roles, and the direction macro level influences steer them.

8.5.4. Implications for further research

Nearly all studies (especially qualitative ones) on infertility and medically assisted reproduction struggle with the problem of reaching men (this is argued by several researchers including Locock and Alexander (2006), Reed (2009) and Szalma (2021a; 2021b)). It should be the aim of further research in all topics regarding infertility or medically assisted reproduction to somehow encourage the participation of men, to find those questions and perhaps innovative methods that could activate the research participation of men, fathers.

9 Conclusions

This last section of the dissertation brings together all earlier elements of the thesis with the goal of moving forward in the realm of social scientific inquiry and promoting progress in the practice of medically assisted reproductive treatments. The subsequent chapter first introduces the relevance of the thesis research from three perspectives, evaluating the dissertation's social scientific contribution to: (1) empirical knowledge about experiencing medically assisted reproduction; (2) theoretical thinking by a combination of sociological approaches earlier not analysed together; (3) methodological novelty of connecting online and offline methods in a multi-method qualitative research design. The conclusion follows with the thesis research's limitations, while simultaneously draws a path for further inquiry. The dissertation finishes with a part presenting recommendations grounded in the findings of the project.

9.1. Interpretation of the findings

The holistic aim of the study was to gain understandings of the experiences of patients participating in medically assisted reproduction treatments in Hungary, adding significant insights to the already existing plethora of Hungarian and international sociological knowledge. 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, as the uses of medically assisted reproductive technologies are becoming more salient since a growing number of couples are experiencing problems with conception. Based on demographic and medical literature introduced in the dissertation infertility and involuntary childlessness will escalate in future decades. 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. The thesis research derives its findings from the patients' first-person recollections and accounts of lived experiences of infertility and MAR treatments, portraying diverse and highly subjective health and illness interpretations.

While this is beneficial for the Hungarian social scientific community, it also has international implications to better understand experiences of infertility and its treatment in pronatalist societies, where parallel to placing significant emphasis on biologically related children, there is a rather generous funding scheme for medically assisted reproduction. Yet despite having supporting policies in place the treatment experience is marred by suboptimal experiences in the health care system, which have direct effects on the doctor-patient relationships and the nature of these interactions.

Secondly, there was an aim to contribute to theoretical sociological knowledge by bringing together multiple sociological approaches that have in this fashion not yet been analysed together. To achieve this goal the theoretical basis of the thesis was grounded in four diverse approaches. Advances in the STS field (Collins and Evans, 2002; Myskja, 2007; Prior, 2003; Rueger, Dolfsma and Aalbers, 2021) were augmented by medical sociologists' ideas on the newly emerging and constantly changing doctor-patient relationship (Cockerham, 2017; 2021; Molnár et al. 2018; Parsons, 1951; Rózsa, 2016;), linking the two fields with specific concepts of biopolitics and the challenges of informed consent (Memmi, 2015). Subsequently the dissertation also identified literature focusing on specific gender roles attributed and performed throughout the patients' treatment pathways, all the while highlighting the role of different online science communication models. Through this combination of approaches the dissertation adds contributions to the plethora of knowledge including the fields of science and technology studies, medical sociology, gender studies and online communications inquiry.

The third major aim of the project was to successfully apply a multimethod approach, combining passive and active research methods within the qualitative paradigm. Namely augmenting the results of a netnography performed on online discussion communities, bringing together patients partaking in medically assisted reproductive treatments, with in-depth qualitative patient interview and semi-structured expert interviews. These exploratory, qualitative findings were contextualized with the help of a series of expert interviews conducted at several infertility clinics. Overall, the methodological findings were that the two highly different data types (online and offline data) brought to light some distinct aspects, and proved to be fruitful for painting an overarching, yet deep portrait of the experiences of women partaking in medically assisted reproduction treatments. While embedding netnographic research to the

methodological toolkit of the Hungarian sociological community has been an important driver throughout the thesis research project, combining netnography and qualitative interviews has international poses novelty for the qualitative research community, relevantly contributing to the increasingly popular and burgeoning multi-method research paradigm. Working with large sets of online trace data utilizing qualitative methodology is in itself novel to in the described fields of sociological inquiry.

To achieve the above emphasized goals, the dissertation strived to investigate and answer four diverse research questions, all stemming from one of the different fields of sociological knowledge. The first exploratory question was looking at how the experiences of the patients were narrated in the online and offline realms, what were the main themes and topics that portrayed their realities and understandings.

In the results of the netnography we found that patient experiences and thus online conversations were structured along the lines of four distinct patient treatment pathways (either linear or cyclical). The painted emotional landscape was very much in line with the stages of the journeys and the actual position of the patients. The fieldwork highlighted how the online discussions and communities played a role in ventilation of problems and pain, skewing the emotions and conversation sentiments towards negativity. Albeit there was significantly less room for positivity (and good evaluations) about the treatment encounters, the conversation communities showed the positive emotions and support towards fellow patients, emphasizing the similarities of their core experiences.

The exploration of the emotional characteristics of the conversation resulted in an expressive emoji map, and a comprehensive patient dictionary including the so-called softening terms or devices (Wallace, 2006) that made the medical terminology less abstract for the patients. The linguistic adaptations also served as a way to achieve and deepen group cohesion and distinction of “inner and outer groups” through mutual communicative understandings.

Comparing the results of the two methodological prongs we can conclude that there are some topics that are not at the top of mind of patients, but their opinions can be successfully accessed via the augmenting active interview methodology. Based on the narrative landscape (where thirteen main thematic drivers of conversations were

identified and detailed), we can say that four themes dominated the discussions: narratives of infertility and childlessness; transfer of knowledge (often in the form of Q&A); relationship with the medical professionals of the Hungarian health care system; and the material burdens that accompany medically assisted reproduction procedures. It is important to note here, that many of these burdens have been lifted by changes in governmental policy and financing of treatments and diagnostics since the end of the data collection. We can also conclude that moral and ethical dilemmas are not at the forefront of patients' thinking and communication about medically assisted reproduction – only scarcely did they appear in online discussions but could be investigated with the interviews (details of moral implications can be read in Vicsek, Bauer and Szolnoki (2019) or Vicsek, Sándor and Bauer (2021)).

Turning towards the second research focus grounded in the theories of science and technology studies also provided insightful findings about Hungarian infertility patients (providing answers for the second research question (RQ2). From this strand of the research, we can conclude that medically assisted reproduction treatments offer a fruitful ground for patients to accumulate substantial and relevant knowledge about conditions, procedures, and contexts. The thesis research unveiled that patients mobilized their knowledges in peer-conversations as well as in their interactions with medical professionals.

Knowledge transfer was one of the main identified themes of the netnographic prong of the thesis research, in which members of discussion communities shared both medical and contextual based lay expertise. This phenomenon could also be grabbed through the special linguistic expressions present foremost in the online data. More experienced and informed members assumed a so-called 'translator-role' utilizing the linguistic softening-devices (detailed in Chapter 8.1.4 and the Appendix of the dissertation) to explain complex terminologies and techniques to the less knowledgeable or new-comer patient participants.

By comparing our findings to definitions of lay expertise introduced by (Myskja, 2007), we can state that Hungarian infertility patients fit the set criteria for lay experts. Based on this thesis research findings we were able to highlight expertise's pertinency in understanding the changes reshaping the doctor-patient relationship, and the role online health information seeking behaviour has on lay patient knowledge. Five main

motivations were identified for knowledge accumulation and utilization foremost in the online data set. The netnographic prong elucidated that discussion community authors 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.

The patient interviews showed us the following: while the expert interviews warned against patients' unbridled acceptance of non-verified and often misleading information.

Next, the thesis research undertook the examination of the portrayals of the doctor-patient relationships. Interactions between the dyad was the in focus of the third formulated research question (RQ3). Our aim here was to understand the forces and mechanisms influencing doctor-patient relationships and how these positive or negative experiences impacted the provided care and patient compliance. The influencing mechanisms identified in the medical sociology section of the dissertation (Chapter 3.3.) were supported by the findings of the thesis fieldwork. Changes in the traditional 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, and from the perspective of biopolitics and biopower (5) patient autonomy through informed consent.

Patients' constructions of their illness and its understandings are impacted by these experiences as well (Cockerham 2017). What we observed via fieldwork connecting the online and offline realms, is that whilst the patients have already moved far away from the traditional submissive and passive sick-role (a main tenet of Parsonian medical sociology (1951)), their professional counterparts still attempted to maintain their authority and the hierarchical relationship of the dyad. Moreover, the patients exhibit behaviours that are much more in line with the Szasz and Hollander (1956) and the Mead and Bower (2000) models that are ultimately patient centric. The thesis research results support the notion that a new type of patient oriented professional communication and

self-presentation is needed (Molnár et al. 2018) to maintain credibility and patient compliance.

This opposing set of interest resulted in salient friction between the actors, which was expressed vehemently. Surprisingly, the patients were very much focused on the supposed negative, malicious intent of doctors, which they attributed to the profit-oriented nature of the private clinics. The hybrid care system brought forth significant frictions – elevating the material dimension of the conversation to one of the most popular themes. These material burdens were seen as unjust restrictions to access or being treated as second-rate patients in the state financed programmes.

The last section of the thesis explores questions related to gender roles, grounded in yet another theoretical frame. Research question four (RQ4: *How do gender roles and gendered genetic responsibility influence the Hungarian patients' narrated experiences?*) was devised to investigate the gendered aspects of MAR. As such, said element of the dissertation looks at the prenatal, infertility and partaking in medically assisted reproduction through the lens of gender roles, relying on theoretical and empirical foundations of gender role theory. Our results concur with those of Szalma (2021a; 2021b) that state that the pronatalist disposition of the conservative government is a crucial influencing factor in the perceptions on medically assisted reproduction.

The pronatalist sentiment does not only place a burden on women on a macro level, but on a micro one as well, as they are steered towards taking on most of the reproductive and genetic responsibility. The thesis research result found that this unequal burden is solidified by the practices of the infertility clinics and the networks of the female patients. Reeds (2012) findings in the UK showed some similarities, but we found that the information gathering role was mainly tied to women. Our findings also support the arguments of Locock and Alexander (2006) who state that when researching reproduction the female perspective dominates, even though the male partners can be eager and willing to participate more actively (Dick, 2011). Attempting to break down these gendered behavioural patterns can lead to less tensions and more active and satisfied participation from couples.

9.2. Limitations and suggestions for future research

Finally, it is important to draw attention to some limitations of the dissertation and the core research. First of all, the research focused only on one side of the partnership partaking in the medically assisted reproduction treatments. As Locock and Alexander (2006) have highlighted this is an overarching problem of studies on reproduction. The reason for this limit was a practical one, with two explanations. Firstly, no public online discussion community at the time of the data collection had salient number (or even any) male members. Secondly, the recruitment of men for patient interviews proved to be extremely difficult, and to get an adequate sample seemed downright impossible. The snowball sampling method in the case of our research proved only to be effective in recruiting women. Almost all the partners of our female interview participants declined to talk to our research team, even when we offered to have a man talk to them.

This limitation also presents an opportunity and a research challenge that should be tackled in the future. It would be beneficial to understand the male perspective, especially if any policy recommendations, or recommendations for medical professionals are to be constructed.

Another limitation was the demographic and educational homogenous nature of the in-depth patient interviews (with regards to other important dimensions concerning medically assisted reproduction the sample composition was more balanced). Albeit it was the intent of the research project to have more diverse sample, the sensitive nature of the topic made it extremely difficult to recruit patient interview participants. Relying foremost on snowball method and online recruitment led to these distortions. The research results are thus not representative but adhering to the notions of Lincoln and Guba (1994) or Noble and Smith (2015) is credible from the methodological standpoint. Whilst based on recruitment experience it seems mostly impossible to present a fully representative patient sample, it is an opportunity for further research to not only aim for the involvement of men, but also a more diverse group of women.

A shortcoming of the research can be identified within its scope as well. The study did not look specifically at limitations to access to medically assisted reproductive treatments based on sexual orientation and age. The reason for this is twofold. First the

topic has been extensively investigated by Szalma, Takács and colleagues, with very recent results as well. Secondly, the question of access did not emerge as a theme organically from the online data, which in the research design served as a pilot investigation for both the later larger netnographic analysis and the patient interviews. Still there is an opportunity here for either research team cooperation, or a topic specific deep-dive online thematic analysis.

Another limitation of the study was its purely qualitative nature. While the multimethod qualitative design surely had its benefits and novelty, combining the qualitative netnography with quantitative content analysis might bring forth further interesting understandings of the unique population. The author of the thesis plans to publish a large-scale, more quantitative focused analysis in the future, and it seems feasible to also add a content analysis strand to further inquiry.

Another shortcoming of the research is its solely Hungarian context. A multi-language, multi-country research could help ground the findings in context, see the influence diverse societies and cultures on the orientations and results. International relevance of this would be that to my knowledge no study has been conducted about medically assisted reproduction with a combination of the four applied theoretical approaches or a multimethod design with one prong being a qualitative netnography.

9.3. Research based professional and policy recommendations

There were several problematic clusters identified during the research, which could be addressed in order to have a more seamless, harmonious and less stressful patient and treatment system encounter.

The four identified problem-hubs are the following: (1) material burdens and inequality of access; (2) streamlined, unpersonal brushes with the infertility treatment facilities and professionals; (3) unaddressed psychological burdens and harms to patient emotional well-being; (4) the lack of adequate opportunity for male partners' presence in treatment practice.

The material burdens were already partly addressed during and at the end of the data-collection period of the research. In theory since the policy measures have become effective all elements (treatment, diagnostics, and medications) of the medically assisted reproduction cycles are free of charge for Hungarian patients who fit the criteria for eligibility. Yet some discussions were seen that there are still medications that are costly. If this is not the case then the recommendation for an educational and communications campaign is valid, because old, out of date knowledge might discourage couples from partaking in treatment.

The second cluster of problems were identified through narratives about the encounters and interactions within the medical system. Patients felt that they were not listened to, or their individual needs were not taken into consideration, they often felt that the process was rushed (causing an extra amount of unnecessary stress), and the professionals' bedside manner was problematic to say the least. Focusing professional and institutional education on a more comprehensible and relatable communication style could benefit both the patients and the facilities in the long run. This recommendation is more explicit for the facilities themselves, but implicitly due to the nationalization should affect policy-thinking as well.

The third identified hub may be the most crucial and solving it would have great benefit for the patients. As the earlier empirical studies and the thesis research underlined both infertility and participating in medically assisted reproduction is a highly stressful life-event, which places significant psychosocial burdens on the patients. While the medical, physical side-effects are addressed by the fertility specialists, these psychological problems or tensions are only dealt with if the patient chooses to attend private therapy or counselling. Results of such sessions are proven to be beneficial for both individuals and couples alike, thus an important recommendation would be to augment infertility treatment with available psychological counselling. Stress is proven to decrease fertility and lessen the chances of conception, so alleviating the tensions in the long-term may even lead to a larger number of births.

The last problem of the obstacles of adequately deep male partner participation is one that has been reported by international literature as well. The issue is manifold in origin and nature. On the one hand, there is the question of male partners not being supportive and willingly present during medically assisted treatment processes. The

grounds for these lays in many macro and micro mechanisms of different societies, moreover, solving the dilemma is vastly out of the scope of this dissertation. On the other hand, the thesis research has identified several instances where participation was desired, but not possible. This poses a particularly intense problem as the more modern and involved father role is increasingly gaining ground. The main obstacles identified were as having difficulty getting time off from work to partake in the myriad of steps involving treatment and the practice of clinics in unnecessarily separating couples. Thus, the recommendation targets both policy makers and facility operating professionals. Firstly, it should be achieved and communicated that the medically assisted reproductive procedures also give special status for men – allowing them to take part freely without being disadvantaged in their work. Secondly, providing opportunity to jointly participate in clinical procedure should be the practice (unless medically advised against) in order to encourage engagement of potential fathers from early on, while simultaneously alleviating the stress of the women through the continuous presence and support of their partners.

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Appendixes

1. Keyword syntaxes

meddő* OR próbálkoz* OR (("nem lehet" OR "nem jön") NEAR/0 (bab* OR gyerek* OR gyermek*)) AND (((inzulin NEAR/0 reziszten*) OR pcos OR policisztá* OR endometriozis* OR endometriózis* OR (pajzsmirigy* NEAR/0 (probléma OR alulműködés)) OR túlműköd*) OR menstruáció OR leiden OR (petevezeték NEAR/0 (működ* OR elzárult)) OR anovuláció OR ciklus OR hormon* OR ((prolactin OR prolaktin) NEAR/0 (sok OR magas* OR túltermel*)) OR ((kevés OR keves* OR alacsony* OR termel*) NEAR/0 (fsh OR LH OR tüszőhormon OR progeszteron)) OR (petesejt NEAR/2 (tapad* OR megtapad* OR beágyazód*)) OR (policisztás NEAR/0 petefész*) OR (sperm* NEAR/0 (lassú* OR kevés OR keves* OR antitest)) OR endó* OR endo* OR hipotireózis OR hipertireózis OR (kromoszóma NEAR/0 (hibás OR betegség)) OR turner* OR (vetélés NEAR/0 (habituális OR ismét* OR autoimmun OR alloimmun)) OR génhib* OR génbetegség OR génmutáció)) AND lang:hu

((meddő* OR próbálkoz* OR (("nem lehet" OR "nem jön") NEAR/0 (bab* OR gyerek* OR gyermek*)) AND (stimu* OR lombik OR inszem* OR (fagyaszt* NEAR/2 (beültetés OR embrió* OR petefészekszövet OR tárol*)) OR (fagy* NEAR/0 (baba OR babá*)) OR fagyibab* OR ivm OR (petefészek NEAR/2 fagyasztás) OR beültetés OR "asszisztált terhesség" OR FET OR ivf OR pic* OR icsi OR embriótranszfer OR tüszőpunkció* OR opu*)) AND lang:hu

((meddő* OR próbálkoz* OR (("nem lehet" OR "nem jön") NEAR/0 (bab* OR gyerek* OR gyermek*)) AND ((t3 OR t4 OR anti-tpo OR tsh OR amh OR fsh OR prog* OR progeszteron OR ösztrogén OR anti-müller OR gn* OR tüszőszám OR tsh OR prolaktin) NEAR/2 (ovu OR ET OR érés OR ciklus OR szint* OR érték*)) AND lang:hu

(meddő* OR ((próbálkoz* OR ("nem lehet" OR "nem jön")) NEAR/0 (bab* OR gyerek* OR gyermek*)) AND ((róbert NEAR/0 károly*) OR SOTE OR kaáli* OR forgách* OR forgács* OR versys* OR dévai* OR bmc* OR ciris OR (szent NEAR/0 jános*) OR budai* OR ((pécs* OR szeged* OR jános*) NEAR/2 (reprodukciós OR meddőségi OR klinik* OR centrum* OR kórház* OR központ*)) AND lang:hu

(((((inzulin NEAR/0 reziszten*) OR pcos OR policisztá* OR endometriozis* OR endometriózis* OR (pajzsmirigy* NEAR/0 (probléma OR alulműködés)) OR túlműköd*) OR menstruáció OR leiden OR (petevezeték NEAR/0 (működ* OR elzárult)) OR anovuláció OR ciklus OR hormon* OR ((prolactin OR prolaktin) NEAR/0 (sok OR magas* OR túltermel*)) OR ((kevés OR keves* OR alacsony* OR termel*) NEAR/0 (fsh OR LH OR tüszőhormon OR progeszteron)) OR (petesejt NEAR/2 (tapad* OR megtapad* OR beágyazód*)) OR (policisztás NEAR/0 petefész*) OR (sperm* NEAR/0 (lassú* OR kevés OR keves* OR antitest)) OR endó* OR endo* OR hipotireózis OR hipertireózis OR (kromoszóma NEAR/0 (hibás OR betegség)) OR turner* OR (vetélés NEAR/0 (habituális OR ismét* OR autoimmun OR alloimmun)) OR génhib* OR génbetegség OR génmutáció))) AND ((stimu* OR lombik OR inszem* OR (fagyaszt* NEAR/2 (beültetés OR embrió* OR petefészekszövet OR tárol*)) OR (fagy* NEAR/0 (baba OR babá*)) OR fagyibab* OR ivm OR (petefészek NEAR/2 fagyasztás) OR beültetés OR "asszisztált terhesség" OR

FET OR ivf OR picsei OR icsei OR embriótranszfer OR tüszőpunkció* OR opu*)) AND lang:hu

(((((inzulin NEAR/0 reziszen*) OR pcos OR policisztá* OR endometriozis* OR endometriózis* OR (pajzsmirigy* NEAR/0 (probléma OR alulműködés)) OR túlműköd*) OR menstruáció OR leiden OR (petevezeték NEAR/0 (működ* OR elzárult)) OR anovuláció OR ciklus OR hormon* OR ((prolactin OR prolaktin) NEAR/0 (sok OR magas* OR túltermel*)) OR ((keves OR keves* OR alacsony* OR termel*) NEAR/0 (fsh OR LH OR tüszőhormon OR progeszteron)) OR (petesejt NEAR/2 (tapad* OR megtapad* OR beágyazód*)) OR (policisztás NEAR/0 petefész*) OR (sperm* NEAR/0 (lassú* OR kevés OR keves* OR antitest)) OR endó* OR endo* OR hipotireózis OR hipertireózis OR (kromoszóma NEAR/0 (hibás OR betegség)) OR turner* OR (vetélés NEAR/0 (habituális OR ismét* OR autoimmun OR alloimmun)) OR génhib* OR génbetegség OR génmutáció) AND(((t3 OR t4 OR anti-tpo OR tsh OR amh OR fsh OR prog) OR progeszteron OR ösztrogén OR anti-müller OR gnrr OR tüszőszám OR tsh OR prolaktin) NEAR/2 (ovu OR ET OR érés OR ciklus OR szint* OR érték*)) AND lang:hu

(((((inzulin NEAR/0 reziszen*) OR pcos OR policisztá* OR endometriozis* OR endometriózis* OR (pajzsmirigy* NEAR/0 (probléma OR alulműködés)) OR túlműköd*) OR menstruáció OR leiden OR (petevezeték NEAR/0 (működ* OR elzárult)) OR anovuláció OR ciklus OR hormon* OR ((prolactin OR prolaktin) NEAR/0 (sok OR magas* OR túltermel*)) OR ((keves OR keves* OR alacsony* OR termel*) NEAR/0 (fsh OR LH OR tüszőhormon OR progeszteron)) OR (petesejt NEAR/2 (tapad* OR megtapad* OR beágyazód*)) OR (policisztás NEAR/0 petefész*) OR (sperm* NEAR/0 (lassú* OR kevés OR keves* OR antitest)) OR endó* OR endo* OR hipotireózis OR hipertireózis OR (kromoszóma NEAR/0 (hibás OR betegség)) OR turner* OR (vetélés NEAR/0 (habituális OR ismét* OR autoimmun OR alloimmun)) OR génhib* OR génbetegség OR génmutáció) AND(((róbert NEAR/0 károly*) OR SOTE OR kaáli* OR forgách* OR forgács* OR versys* OR dévai* OR bmc* OR ciris OR (szent NEAR/0 jános*) OR budai* OR ((pécs* OR szeged* OR jános*) NEAR/2 (reprodukciós OR meddőségi OR klinik* OR centrum* OR kórház* OR központ*)))) AND lang:hu

((((stimu* OR lombik OR inszem* OR (fagyaszt* NEAR/2 (beültetés OR embrió* OR petefészekszövet OR tárol*)) OR (fagy* NEAR/0 (baba OR babá*)) OR fagyibab* OR ivm OR (petefészek NEAR/2 fagyasztás) OR beültetés OR "asszisztált terhesség" OR FET OR ivf OR picsei OR icsei OR embriótranszfer OR tüszőpunkció* OR opu*)) AND(((t3 OR t4 OR anti-tpo OR tsh OR amh OR fsh OR prog) OR progeszteron OR ösztrogén OR anti-müller OR gnrr OR tüszőszám OR tsh OR prolaktin) NEAR/2 (ovu OR ET OR érés OR ciklus OR szint* OR érték*)) AND lang:hu

((((stimu* OR lombik OR inszem* OR (fagyaszt* NEAR/2 (beültetés OR embrió* OR petefészekszövet OR tárol*)) OR (fagy* NEAR/0 (baba OR babá*)) OR fagyibab* OR ivm OR (petefészek NEAR/2 fagyasztás) OR beültetés OR "asszisztált terhesség" OR FET OR ivf OR picsei OR icsei OR embriótranszfer OR tüszőpunkció* OR opu*)) AND(((róbert NEAR/0 károly*) OR SOTE OR kaáli* OR forgách* OR forgács* OR versys* OR dévai* OR bmc* OR ciris OR (szent NEAR/0 jános*) OR budai* OR ((pécs* OR szeged* OR jános*) NEAR/2 (reprodukciós OR meddőségi OR klinik* OR centrum* OR kórház* OR központ*)))) AND lang:hu

((((t3 OR t4 OR anti-tpo OR tsh OR amh OR fsh OR progesteron OR ösztrogén OR anti-müller OR gnrh OR tüszőszám OR tsh OR prolaktin) NEAR/2 (ovu OR ET OR érés OR ciklus OR szint* OR érték*)) AND ((róbert NEAR/0 károly*) OR SOTE OR kaáli* OR forgách* OR forgács* OR versys* OR dévai* OR bmc* OR ciris OR (szent NEAR/0 jános*) OR budai* OR ((pécs* OR szeged* OR jános*) NEAR/2 (reprodukciós OR meddőségi OR klinik* OR centrum* OR kórház* OR központ*)))) AND lang:hu

2. Patient dictionary

New term	Hungarian original	English translation
alszik a pocakomban	állapotos	pregnant
babásodás	teherbe esés	pregnancy
babát visszakapni	fagyasztott embrió felhasználása	using vitrified embryo
babázunk	teherbe esés	pregnancy
babóca	kisbaba	baby
barnázás	barna folyás	brown mucus
béby	kisbaba	baby
beülti	beültetés	embryo transfer
beülti	embrió beültetés	embryo transfer
closty	clostilbegyt tableta	clostilbegyt tablets
cytó	citológia	cytology
emberpalánta	embriók	embryos
eperkéim	embriók	embryos
fagyasztott bábik	fagyasztott embrió	vitrified embryo
fagy	fagyasztott embrió	vitrified embryo
fagyibaba	fagyasztott embrió	vitrified embryo
fagyibébi	fagyasztott embrió	vitrified embryo
fagyis	fagyasztott embrió	vitrified embryo
fagyizás	embryo fagyasztás	embryo vitrification
felébresztik őket	felolvasztott fagyasztott embriók	thawed vitrified embryos
férjem anyaga	spermium	sperm
fészek	petefészek	ovaries
fickók	spermium	sperm
foltockáim	embriók	embryos
hiperstimu	hiperstimuláció	hyperstimulation
hormszuri	hormone injekció	hormonal shot
inszem	inszemináció	insemination
katonák	spermium	sperm
kis bogyók	embriók	embryos
kisbabó	kisbaba	baby
kismamik	állapotos	pregnant
konzi	konzílium	specialist visit
leadni a fiúkat	sperma minta	to give a sperm sample
lombik	In vitro fertilizáció	In vitro fertilization (IVF)

New term	Hungarian original	English translation
lombikbaba-projekt	ivf ciklus	IVF cycle
lombikbébi	in vitro kezeléssel fogant kisbaba	baby conceived in vitro
lombikgyerek	in vitro kezeléssel fogant kisbaba	baby conceived in vitro
lombikgyerkő	in vitro kezeléssel fogant kisbaba	baby conceived in vitro
lombikgyerkőc	in vitro kezeléssel fogant kisbaba	baby conceived in vitro
lombikklub	ivf kezelésben részesezők	IVF participants
málnácskák	embriók	embryos
megkapaszkodott megy a lefolyóba	sikerese beültetés megsemmisítik a be nem ültetett embriókat	successful embryo transfer discarded embryos
mensi	menstruáció	menstruation
mentek a fagyiba	embryo fagyasztás	embryo vitrification
merk	Merkformin	Merkformin
met	Metformin	Metformin
miki	menstruáció	period
mikulás	menstruáció	period
nődoki	nőgyógyász	gynaecologist
nőgyógyi	nőgyógyász	gynaecologist
nőgyógyi	nőgyógyász	gynaecologist
Ovi	Ovestin krém	Ovestin creme
ovu	ovuláció, peteérés	ovulation
Pari	Parádfürdő	destination in Hungary with thermal water supposedly beneficial for infertility patients
pé	peteérés	ovulation
pocaksimi	állapotos nő hasának simogatása	rubbing a pregnant belly
priviben	privát üzenetben	in direct message
progi	progeszteron	Progesterone
progi nézés	progeszteron mérés	Progesterone level checking
progikrém	progeszteron tartalmú krém	progesterone hormonal ointment
régi barátném	menstruáció	period

New term	Hungarian original	English translation
stimu	petefészek stimuláció	ovarian stimulation or ovarian induction
szedrecske	embriók	embryos
szép a progid	megfelelő progeszteron szint	healthy progesterone level
tüszőrepi	tüszőrepedés	follicular rupture, ovulation
újmeddő	újonnan diagnosztizált páciens	newly diagnosed infertility patient
visszakapjuk őket	felolvasztott fagyasztott embriók	thawed vitrified embryos
visszakérjük őket	felolvasztott fagyasztott embriók	thawed vitrified embryos
vv	vérvétel	blood work

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