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The human embryo: Mapping patients' ethical decisions in Hungary

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Abstract

When in vitro fertilization (IVF) treatments first appeared in Hungarian legislation, the related experiences and the moral dilemmas of couples who go through these procedures were unknown. Couples have to make a great variety of decisions during the IVF process. In our study, we focus on the journey of the human embryo in IVF treatment through the ethical lenses of women. In order to explore the differences between established ethical and legal frameworks and the perspectives of women who have participated in an IVF procedure in Hungary, we conducted semi-structured interviews. In contrast to the static view of embryos typical to a part of the ethics literature, which also characterizes most established legal frameworks, patients' view of embryos of interviewees was dynamic: they interpreted embryos in a malleable and constantly changing way. Embryos were perceived differently depending on time, place, and biological characteristics, and primarily in relation to how they could contribute to achieving the goals of treatment. In this article, we also demonstrate that the main ethical framework that the participants in our research evoked in relation to the IVF process was related to the ethics of medical treatment. At the end of the paper we also make an attempt to draw some conclusions that may help ameliorate problems with the current normative ethical and legal framework by incorporating the experiences of women who participate in IVF procedures.

Keywords: bioethics, embryo, qualitative study, assisted reproduction

1 Introduction

Since the first baby was born in 1978 with the assistance of in vitro fertilization (IVF), millions of children have come into the world via artificial reproductive technologies. Looking closer at the practice of this reproductive technology, it is easy to see that the technopolitical culture of different countries varies greatly in relation to this procedure (Felt et al., 2010). The culture of assisted reproduction in a country can be characterized

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by the way embryos are viewed and treated, and the way ethical considerations guide technopolitical decisions concerning embryos. Earlier research on the conceptualization and definition of embryos and the decision-making process based on these focused mainly on those countries in which there was strong emphasis on open, public debate about the moral status of the embryo. Our current research explores the ways embryos are viewed in Hungary, where until the beginning of this research no public debate about these issues had taken place. This study examines patients' ethical decisions at the intersection of sociology, bioethics, law, and science and technology studies (STS). It maps out the ethical frameworks applied in the accounts of IVF customers when they discuss decisions they made involving the moral status of the embryo. Within the framework of this research, we conducted 20 semi-structured interviews with women.

There are countries where four to five percent of all babies are born as a result of in vitro fertilization (IVF) procedures. The scope of application of IVF has also become increasingly wide in Hungary, where, according to estimations by the authorities, 1.5 to 2 per cent of all babies are born with the help of in vitro techniques (Szülészeti és Nőgyógyászati Szakmai Kollégium, 2010), and it is expected that this figure will increase due to a variety of social and biological developments (Anderson, 2005; Boivin et al., 2007).

The spread of assisted reproductive technologies¹ is transforming earlier views about how to define such notions as the body and the family, nature, and life (Perrotta, 2013). Using reproductive and other biomedical technologies raises numerous ethical, moral, and social questions (Sándor, 2009); while some authors compare the significance of the former to that of the emergence of nuclear technologies in the middle of the twentieth century (Thompson, 2005).

In this article, we analyze perspectives and ethical frameworks related to the embryo in the IVF process.

Many authors use the terms 'embryo' and 'fetus' in different ways, and there are different conceptions of them in different legal frameworks as well. An important biological definition of the human embryo considers it to be a discrete entity that has arisen either due to fertilization of a human egg by a human sperm, or by other processes such as cloning, whereby a biological entity with a human nuclear genome is created. It is an important distinction that 'embryo' is the term for this biological entity for the first eight weeks of development only, while after that it is referred to as a 'fetus' in the biological literature (Findlay et al., 2007).

The IVF procedure is a type of artificial reproductive technology in which the fertilization of eggs takes place outside the uterus (in vitro, i.e. outside the body). During the IVF process patients have to make a number of difficult decisions about the fate of embryos. During the procedure, as a result of hormonal simulation, many eggs are typically available, and thus more embryos are created than are transferred into the womb. This raises the issue of what to do with surplus embryos—embryos which are left over after the procedure. These embryos can, for example, be frozen and stored for later use. However, it may happen that after successful pregnancy/pregnancies, some stored embryos remain unused. In some countries it is possible to donate embryos for research—for example, stem

In this paper, assisted reproductive technologies are understood as various forms of treatment and procedures designed to achieve pregnancy involving the treatment of eggs, sperm, and embryos in the laboratory. One of these procedures is in vitro fertilization (Zegers-Hochschild et al., 2009, p. 1521).

cell research. There is also often the possibility to donate them to other couples. These are just examples of some of the difficult choices that need to be made.

The aim of the current article is to investigate the morality of patients. Several sociologists (Bauman & May, 2001; Sayer, 2004) argue that within sociology too little attention has been paid to the moral aspects of social life. Sayer (2004) argues that in people's lives it is often normative issues that are the most important ones. This does not mean that individuals always consciously or directly think about moral issues many times a day: some of our moral thinking has resulted in habitual action, meaning that people do not always engage with the moral component actively. Under the term 'lay morality,' in this article we understand the morality of non-experts that deals with 'questions of what concrete behaviors or practices are good or bad, how we or others should behave and what we or others should do' (Sayer, 2004, p. 3). Following Sayer's approach, we connect morality to emotions and well-being, regarding the moral aspect as relating to things that people care about and positing that it affects people's well-being. From this perspective, emotions are regarded to have a cognitive character and are not necessarily seen to be opposed to reason and rationality.

During the analysis we seek to answer the following research questions:

- (1) What kind of ethical frameworks do Hungarian women who participate in IVF procedures use in their decisions related to the fate of embryos?
- (2) How do they view embryos within these ethical frameworks?

Our aim is to compare the views of women who undergo procedures with those embedded in bioethical and legal frameworks.

While in many countries in the world serious public debate has taken place about the moral status of the embryo (Gaskell et al., 2006; Gottweis, 2002; Kirejczyk, 2008; Reis, 2008), this discussion was neglected in Hungarian society until the summer of 2017 when Bishop András Veres put ethical dilemmas related to the embryo and the surrounding artificial reproductive technologies somewhat into the limelight. However, we conducted our research and collected empirical data before this date, so his raising the topic did not influence the content of the interviews.

In certain countries (e.g. Italy), the debate has focused on the procedure and the methods applied during artificial fertilization itself. The dilemma concerns whether it is ethically acceptable to allow methods to be used that produce surplus embryos, or whether many embryos may be produced that can be transferred into the body of the woman. In the latter case, the success rate is significantly lower, and the expense of the procedure is also greater (Perrotta, 2013). In other countries, the utilization of surplus embryos for research purposes has been contested: embryonic stem cell research is viewed as the most controversial of potential research applications. The source of controversy is that the related embryos are side products of artificial fertilization procedures, and only two extreme positions have emerged in debate: full commitment to embryonic stem cell research, and complete rejection of it (Kitzinger, 2007).

In Hungary, the law permits the use of in vitro fertilization and the freezing of surplus embryos. As donation for research is not typically an option in Hungary, couples face the decision to either freeze and store surplus embryos, or to permit their destruction. The third option of donating to other couples is extremely rarely available.

The current conservative government, which was already in power in 2013, enshrined the protection of embryos into the Hungarian Fundamental law (constitution), where, according to certain interpretations, this limits options for artificial reproduction. Nevertheless, these theoretical limitations have not seemed to affect the practice of in vitro fertilization, and infertile couples are even being encouraged to take advantage of artificial reproduction in government rhetoric.

According to representative surveys in Hungary, the population has a generally positive view of artificial insemination (Szalma, 2014; Szalma, 2016; Zavecz Research, 2017). In relation to this, other empirical research has also confirmed that Hungarian society values children highly, and respondents emphasize the importance of having their own children (Miettinen-Szalma, 2014; Szalma, 2014). Encouraging couples to have children is also a priority in the political sphere; many new measures have been introduced recently to facilitate childbirth. Similarly to individuals of other countries, Hungarians also prefer a blood relationship between parent and child. As a result, the intention to have a child is evaluated more positively when it involves a genetic relationship between parent and child than when it takes the form of adoption (Neményi & Takács, 2015). In addition, official policy is prenatal in nature.

What makes this research particularly relevant is that we do not yet have information about how Hungarian women who take part in *in vitro* fertilization programs view embryos in general, and what kind of ethical considerations frame their decisions about the fate of embryos.

The paper proceeds as follows. First, we briefly discuss bioethical, sociological, and STS literature which deals with the embryo and with lay morality related to decisions about embryos in IVF. Next, legal frameworks related to the embryo are described. Then the current research project is presented. In the conclusions segment, results are connected to the previous parts of the article. The relationship between the frameworks used in ethics and law is compared with the perspectives of interviewees and found to be different in many respects. The conclusion reflects on the relevance of the results for experts as well as policymakers. The arguments put forward in this article can benefit sense-making concerning the embryo and ethical frameworks, and may prove useful in policy development. It is argued that the perspectives of women who engage in artificial reproduction should be considered when protocols and legislation are designed.

2 Ethical frameworks and the moral status of the embryo

The moral status of the embryo has been debated in ethical literature for a long time. In Warren's definition (1997, p. 3), for a [biological] entity to have moral status, it 'is to be morally considerable,' and 'it is to be an entity towards which moral agents have, or can have, moral obligations.' There are different types of moral statuses, and bioethicists have not reached agreement on which kind of moral status the embryo has. Some authors assign a moral status to embryos that relates them to things (Warren, 1997) but not human beings, while others—from the point of view of Catholic theology, for example—would assign almost the same moral status to them as to adults (Shannon & Wolter, 1990). Some view them as mere aggregations of human cells, while others as human beings (Warnock, 1985). What is common to such a wide range of (sometimes diametrically opposing) views is that

they often discuss the moral status of 'the' embryo – as if embryos are to be considered only one type of entity. This static view of the embryo is dominant and well established in the bioethics literature, although some authors distinguish between, for example, the age, or the location of the embryo. Still, the latter do not typically involve nuanced classification systems but rather only differ in terms of the criteria employed to determine if the embryo has moral status: thus, the embryo is regarded either as having moral status, or not. Some authors, for example, are of the position that the embryo can be considered the start of a human life at the age of 14 days (Nakano-Okuno, 2006), while others assign it moral status only when it has a functional relationship with the mother's womb (Agar, 2007).

The literature in sociology and science and technology studies (STS) emphasizes that embryos are not only material but also socio-cultural entities, so social and cultural factors influence how we think about them (Franklin, 2013). The embryo often does not appear as a kind of entity in these studies, but the latter take into account that, in reality, embryos occur in different specific situations. These differences can affect how social actors perceive them and what moral, ontological, and social status they attribute to them (Franklin, 2013; Perrotta, 2013).

The meanings assigned to embryos are the products of the 'technopolitical culture' of IVF (Felt et al., 2010). In line with this, Latour (1991) and Akrich (1992) emphasize the interrelated development of political and technological configurations and point out that various societies might show cultural differences in how this development occurs. Analyzing various views (judgments) of biomedical technologies, they reach the conclusion that in spite of global (technocultural) trends and the European harmonization of legal norms, there can be great differences in the technopolitical culture of individual societies, the configurations of how these technologies are present in these societies, and the ways in which members of society view these technologies. In their research, Haimes et al. (2008) also emphasize that, depending on the social context, there can be great differences between views about embryos.

Empirical research in the twenty-first century has mainly focused on single decisions regarding the embryo out of the many decisions that patients have to make during IVF—for example, whether to donate to research, etc. (De Lacey, 2007; Frith et al., 2011; Jin et al., 2013.; Roberts, 2007; Waldby, 2014). Most of these research projects were conducted in countries where there has been intensive public debate about the moral status of the embryo and a focus on one decision within the whole process. As opposed to this, the current research explores a wider spectrum of decision-making processes. A further novelty of our research is that it was conducted in Hungary, a country in which the social context of decision-making is different in many regards to in the countries discussed in previous research. Also, according to our knowledge, no other sociological research has examined the lay ethical frameworks related to making decisions about the future of embryos in IVF procedures in Hungary.

Roberts (2007) analyzed decisions about whether to freeze viable surplus embryos after the successful transfer of embryos to the womb. In fieldwork conducted in Ecuador, the author found that IVF clinic personnel and patients employed a variety of ethical interpretations. Some thought according to a life ethical framework, while others within a kinship ethical frame (Roberts calls a 'kinship ethical framework' when embryos are considered

a part of kinship relations) (Roberts, 2007). People who applied this frame expressed fear that their frozen embryos may leave the web of kinship relations and somehow come to be used by strangers without their consent. As opposed to this, according to the more abstract 'life ethical framework,' the embryo is not considered important because it is potentially part of the family, but rather because of an abstract principle it is considered universally valid. This perspective involves treating every single embryo as valuable as it is connected to life, regardless of whether it is connected to a family. Those who thought in terms of the life ethical frame had favorable opinions about freezing embryos, while those who were influenced by the norms of kinship ethics had negative views—and as a result, certain clinics froze significantly fewer embryos than others.

A research team led by Jin (2013) focused on a group of Chinese patients who had completed in vitro fertilization treatment, already had a genetically related child, and had had their frozen embryos stored. They found that the moral status of the embryo was a significant factor for those who decided to continue freezing them, while the high cost of storage was cited among those who decided to stop the freezing process. (It should be noted here that the specificities of Chinese culture and the one-child policy make the Chinese sample unique.)

Even though ethical views about embryos have been analyzed according to different, specialized sub-populations of IVF patients in earlier research projects (for example, those who gave birth using donated eggs, or those who were asked to donate embryos for research purposes after IVF was successful), some shared conclusions can be drawn from these different research efforts.

International research has shown that the embryo may be viewed differently depending on whether it is placed in the womb, or whether it is frozen outside it (Provoost et al., 2011), and individuals who take part in IVF procedures in different countries also show diversity in how they think about and treat embryos (Haimes et al., 2008).

When research on assisted reproductive technologies focused on the health personnel of IVF clinics, ethical issues were mostly connected to one aspect of the decision, similarly to in other earlier research on patients. In the case of personnel, for example, many articles deal with ethical questions related to preimplantation genetic diagnosis (PGD) or the ethical interpretation of donating embryos for research purposes (Baruch, 2008; Ehrich et al., 2010; Ehrich et al., 2011; Kalfoglou et al., 2005; Meister et al., 2005; Wennberg et al., 2016).

In their research about how clinical personnel and researchers viewed and used surplus IVF embryos for stem cell research purposes in Denmark, Svendsen and Koch (2008) found that embryos were considered within a medical-treatment-centered ethical framework. Not being the main focus of their research, the authors do not elaborate on the specificities of this ethical framework; they simply note that this type of ethical thinking is characterized by putting patients' interests above those of the embryo. Svedsen and Koch also found that 'spare' embryos were not in fact simply biological 'facts': complex organizational and moral processes led to the decision whether to select surplus embryos for utilization at a neighboring research clinic.

3 The legal notion of the human embryo

In this section, we examine how jurisprudence regards the status of the embryo and the fetus. For a long time, law was comfortable with the *static* notion of the fetus. The only demarcation line involved (live) birth, the point at which a human being gained legal status. Until the moment of birth, only conditional legal status was granted to the fetus (Yan, 2007). Its different stages of development became relevant first in the context of abortion, and later in the case of IVF, in relation to which an embryo outside of the human body is regarded differently than a fetus in the womb. In Roman law, the *nasciturus*—the fetus in the womb—was recognized in the law of inheritance. This Roman principle of law can be translated as '[t]he unborn is deemed to have been born to the extent that his own benefits are concerned' and influenced European legal thinking about the human fetus for centuries. In the context of abortion, right-to-life, right-to-dignity, and the right-to-privacy have been interpreted. Since the landmark American case Roe v. Wade (Roe v. Wade 410 U.S. 113 1973), the trimester framework has been employed to infer a gradual increase in the rights of the fetus. The turning point is viability.

Although debates about abortion still arise in many parts of the world, dilemmas concerning embryos are much more complex than in the case of the fetus. The complexity stems from the many different technologies which deal with the *in vitro* (outside of the living organism) and *in vivo* (within the living organism—in the uterus) embryo.

Today, scientists distinguish many different kinds of embryos according to by which procedure the embryo was created, and what stage of development the embryo is at. Another categorization may be based on the embryo's role in reproduction. There are embryos for implantation, discarded embryos, embryos to be stored or frozen, embryos for research purposes, embryos for stem cell research, etc. While these technologies raise many different legal concerns, the redefinition of the human embryo in law nonetheless rarely happens. From this static position, many controversial conclusions can be drawn, such as that cloned embryos would not be considered embryos if the law defined embryos only as 'fertilized eggs,' for example.

Since the options created by IVF and the various uses of embryos in different reproductive procedures and in stem cell research have increased, it has become more and more complicated to define the human embryo and what the status and the distinction between various kinds of human embryos may be.

It seems obvious that the status of the *in vitro* and *in vivo* embryo is different. An in vivo embryo has a 'bond' with the pregnant woman, while an in vitro embryo has an uncertain future that includes either a successful implantation and development, or becoming a 'surplus' or 'left over' embryo. Birth still remains the major legal watershed, although when the European Court of Justice faced the issue of the patentability of human embryonic stem cells, it came out with another definition that is applicable in the field of intellectual property law. In *Oliver Brüstle vs. Greenpeace eV.*, the main question was whether stem cells obtained from 5–6 day old human embryos can be regarded as embryos. Unlike the previously static notion of the human embryo, here the Court provided a different definition of the human embryo, but one limited to the domain of biotechnological invention. The aim was clearly to prevent the commercial use of embryos with the purpose of creating embryonic stem cells for patent-related purposes. From this perspective—in accordance with the meaning of Article 6(2)(c) of the Directive 98/44/EC on the legal protection of

biotechnological inventions—, any human ovum after fertilization, and any non-fertilized human ovum into which the cell nucleus from a mature human cell has been transplanted, and any non-fertilized human ovum whose division and further development have been stimulated by parthenogenesis, constitutes a 'human embryo.' Later on, the Court gave a slightly different interpretation in the case of the parthenogenetic activation of an unfertilized ovum (Bovenberg et al. 2016). In this judgement, made in 2014, the European Court of Justice reversed its 2011 ruling, stating that an unfertilized human ovum stimulated by parthenogenesis 'does not constitute a human embryo, if it does not in itself have the inherent capacity of developing into a human being.'

Ascertaining the moral status of the human embryo has many important legal consequences. One is who decides about the destiny of an (*in vitro*) embryo. If embryos are regarded as a kind of shared genetic material, then the mutual consent of the egg and sperm donor or by the prospective parents is necessary. This dilemma was made clear in numerous legal cases, such as in *Evans v. the United Kingdom* (application no. 6339/05) at the European Court of Human Rights (2007). If the law considers embryos as a 50–50 per cent combination of genetic material, then joint consent is necessary for making decisions about the implantation, storage, and destruction of the human embryo. If the law recognizes the in vitro human embryo as a form of production that involves hormonal treatment and invasive medical intervention for women, then the weight of decision-making about the in vitro human embryo may not be symmetrical: women may have priority or more voice about what may or should be done with them (as in Hungarian law, for example).

Looking specifically at Hungarian law, within the Hungarian Health Care Act of 1997 (Chapter IX) a specific chapter deals with assisted reproductive procedures. The chapter starts with some definitions. Embryos are defined as all live human embryos after fertilization until the twelfth week of pregnancy. This definition runs somewhat counter to the content of Parliamentary Act No LXXIX of 1992 on the protection of fetal life. According to this Act, life deserves respect and protection from the point of conception. The 1992 Act nevertheless allows the termination of pregnancy until the twelfth week. While the 1992 Act focusses on the fetus, in Chapter IX the 1997 Act focusses on the human embryo. When this specific chapter on assisted reproduction was designed, the primary focus was to permit a broad scope of various reproductive procedures that mimic natural reproduction.

In Hungarian law, research on embryos is allowed until the fourteenth day following fertilization (Section 181 (1) of the Hungarian Health Care Act). Embryos cannot be created for research purposes. From this it follows that only *surplus* embryos can be used for research based on the consent of patients, and only after the Human Reproduction Commission has approved the related research protocol. Despite the burgeoning IVF sector and the legal possibility of the latter in Hungary, there has basically been no research on the human embryo. Although research on human embryos is allowed in Hungary, there is an aura of secrecy around this practice. This can be explained by various factors: while research on human embryos requires good research facilities, it contradicts the current political-ideological stance of the government. In addition, research on iPS (induced pluripotent stem cells) is within the portfolio of many international research consortia in which Hungarian scientists participate. Moreover, many clinics interpret the laws in the way that surplus embryos cannot be used for stem cell research. Obviously, this goes beyond the

focus on IVF treatment, but some people may wish that their sacrifice has not been meaningless, even if treatment was not successful. A similar approach can be observed in a case at the European Court of Human Rights, *Parrillo v. Italy* (Application no. 46470/11, 2015), in which the applicant complained that her unused embryos could not be donated for research purposes because of legal changes in Italy.

As we have seen, because of serious legal consequences the law creates a strict demarcation line between the person and the human fetus yet to be born. One of the basic conditions of the rule of law is that legal regulations are predictable. As a consequence, whenever it is possible, precise and clear legal categories are constructed. Coherent and strict definitions have to be formulated regarding exactly what research is, about what constitutes a human embryo or a surplus embryo, and when is it possible to make an embryo selection or to implant an embryo. Nevertheless, new reproductive technologies constantly challenge this static vision and – in relation to judicial decisions made on a case by case basis that involve the right to decide about in vitro embryos, and when commercial and research interests jeopardize the adequate protection of embryos – one can see a more nuanced, more dynamic vision of the human embryo. However, overall, the main parts of established legal frameworks remain static in this regard in many countries, including in Hungary.

4 Data and methodology

During the exploratory phase of our research we conducted semi-structured interviews with 20 women who had participated in an in vitro fertilization procedure. We filtered out those women for whom an embryo had not been implanted yet, or who had their last IVF cycle more than three years ago. Two of the interviews took place in Budapest, and the rest in other cities in Hungary. The youngest of the interviewees was 30 years old, the oldest 43. With some exceptions, the majority of them had already had more than one embryo transfer. Twelve interviewees had no children at the time of the interview, but two of them were at a late phase of pregnancy. Thirteen respondents declared themselves religious, and some of them expressly stated that they were Catholic. Half of the interviewees said that they had experience only with Budapest clinics, while the rest had attended IVF clinics in the countryside or both in Budapest and in a smaller city in the countryside. Respondents were recruited in two ways: some of them responded to our call on thematic internet discussion groups and forums, while others were selected through snowball sampling.

The length of the interviews was typically between one and two hours. Because we were examining a sensitive topic with a vulnerable population, we took special care during the interviews to become emotionally attuned to the interviewees. We found that even though difficult emotional situations were often reported, many seemed to find opportunity to be able to speak freely to an understanding audience about their experiences and emotions to be a good experience.

Interviews took place mainly between April 2015 and November 2015.

When evaluating the results, selection effect should also be taken into account, as it is expected that those who are prepared to give such interviews may differ from those who are not. Presumably, those who did not have a bad conscience about the IVF procedure (for example, due to their religious beliefs) were more likely to participate in the research.

During the research we kept in mind the need for anonymity: data have been modified in the analysis so that interviewees cannot be identified (the study uses pseudonyms). All interviewees signed informed consent forms, in which they were informed about the research.

Prior to the period of data collection, ethics approval for the project was obtained from the Ethics Committee of the Faculty of Social Sciences at Corvinus University of Budapest in March 2014.

The results were analyzed using qualitative thematic analysis following the recommendations of Braun and Clark (2006). Interview transcripts as well as our field research notes and electronically accessible content (e.g. websites) were coded using NVivo software. We examined what repetitive thematic patterns could be observed in the corpus. The categories of analysis were formed partly on the basis of theory and previous research, and partly in an inductive way: on the basis of studying the texts. The coding took place in several rounds: after initial coding, we merged some categories, looked at the relationships between the categories and grouped them (these became main categories and subcategories), then we created new categories in which the interpretation was more pronounced. Taking into account the suggestions of Braun and Clark (2006), we took special care that the coding should be thorough and comprehensive, and that the analysis should not only consist of summarizing and characterizing the interview texts, but also interpreting the texts and embedding them in an interpretive framework.

5 Results

In the following, we discuss the main themes that we established from the interview data. An important theme was the prevalence in the narratives of a hierarchy of embryos, with more worth awarded to certain embryos. Another relevant characteristic of the answers was the concentration of those who viewed IVF from a medical treatment ethics perspective, and what happened was interpreted in this frame. Regarding IVF as a necessity, and as a normal – and in many cases the only – way to deal with infertility was also a recurrent theme. Then, we go on to show how the importance of the goal – having a baby – was characteristic of most patients' interpretations. Finally, we discuss how in the cases of those interviewees who had already had a child through IVF treatment and who had chosen to have surplus embryos stored, additional ethical frames emerged when discussing the dilemmas they faced.

5.1 A hierarchy of embryos

We found that most of the interviewees looked at embryos differently to the static view in some of the ethics literature and the main parts of established legal frameworks. Unconsciously, they had developed a hierarchy of worth of human embryos, with some being deemed more valuable than others. While, for example, life ethics attaches equal value to all embryos and links them to human existence without exception (Roberts, 2007), the dynamic vision that emerged in the case of respondents was characterized by a kind of embryo hierarchy. In this approach, embryos that would bring them closer to achieving their goals were considered more important and valuable—the embryos at the center of attention were more strongly connected to the goal of having a baby. For the most part,

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embryos are not regarded as an abstract embodiment of life, but are connected to respondents' own concrete goals of creating a family (in this, the position is similar to kinship ethics). Therefore, embryos do not have an inherent value in themselves, but the latter is related to how they can contribute to a couple's goal of having a viable pregnancy. At given points in time, embryos that fitted this description were always awarded more prominence. Other embryos that were not selected (whether for biological or other reasons) were out of the scope of focus. A given embryo could be brought back from the periphery of attention and activity if its role in achieving the goal of treatment (the birth of a baby) was reassessed—e.g., an embryo that was first frozen and later thawed for implantation. When frozen embryos were required to be used, they again became important as potential sources of a future child. One can say that the value of life was attached to potentiality, not just to the entity of the embryo.

At the time the embryo was transferred to the womb, our interviewees concentrated on the selected embryos. When they saw them on a computer screen they started to hope for a positive outcome, and after the procedure they focused only on the embryos in the womb, hoping that they would successfully develop. Embryos that were not transferred remained outside the focus of attention:

This is not important in that environment, and in that situation—what is important... is to succeed... then you do not concern yourself with what will happen with the rest. (Sarah)

Before the embryo transfers women spoke about the embryos in terms of numbers and used metaphorical expressions such as bubble or flower, as this is how they saw them on the monitor. This shows the relevance of the factor of place—when the embryos were in the womb, women started to refer to them differently. For some women this was the demarcation point after which they regarded themselves as expectant mothers. Others used the term mother or mum with other women who were in a similar situation, although, as the excerpt shows, the latter terms were still used somewhat ambivalently—partly as a joke, partly seriously:

We also called each other moms jokingly, you know, the girls there. Well, yes, after all, I think it was the case for us after so much time... and we didn't achieve this in a natural way, yet it's a great experience to have an embryo in their womb, so yes. (Angie)

Also characteristic of the thinking of many respondents about embryos that were transferred to the womb was that this process did not necessarily mean that a baby would be born. This was especially noticeable with those who had already gone through several unsuccessful IVF cycles. Therefore, even after embryo transfer, they saw their potential—they did not yet see them as their children, but they already meant more to them than a mere set of cells:

Well, for me, it's mixed, okay, I know it's an initial state of a living being, but I still don't feel it's mine. (Kate)

Another important demarcation line for many respondents was the time of attachment of the human embryo to the wall of the uterus. From that moment on they started to personify the embryo more, and to use expressions such as 'little newcomer.'

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It seemed that the more time the embryo spent in the womb, the more important it became for the mother—there was increasing emotional involvement and use of the expression 'my baby' and 'my child.' Thus, the view changed from regarding embryos in the beginning as a set of cells to the respondents' own children.

5.2 IVF as 'infertility treatment'

When IVF is considered as a form of infertility treatment, then the status of human embryos is awarded much less importance. For various reasons, clinics suggested this option to clients. Partially, this was important for receiving state funding for treatment, but it also served as a convenient way to avoid complex moral issues. Since the aim of the procedure was to 'cure infertility,' the medical context often ignored the complex emotional and psychological elements of childlessness. Couples and single women sometimes preferred to have a child or start a family via IVF treatment, and it often seemed to have been easier to accept the medical model then to look at the various reasons for childlessness. In any case, the medical vision does not distinguish between infertility and childlessness. Having a spouse without a child is simply regarded as a case of infertility, which may be treated at a clinic.

Based on the study of interviewees' accounts, it seems that in most decision-making situations related to embryos the dominant feature was what respondents' own interest was in terms of the success of their treatment, and that the treatment should minimize any difficulty. To characterize this ethical framework, we adopt the terminology of the ethics of medical treatment, which is somewhat similar to the treatment ethics used by Svendson and Koch (2008) to describe professional ethics. It may be said that it is only natural that women undergoing IVF would use such a framework for decision-making—a framework which constructs them as patients, and where the emphasis is on their treatment interest and minimizing financial, workplace, relationship, and health difficulties. However, as we have shown in reference to Roberts' (2007) research, this is by no means necessary. It is conceivable that a woman undergoing IVF may be guided by different considerations in some of her decisions.

Within the ethical framework of medical treatment, even if a decision affected the embryo the justification of the choice did not include considerations related to the embryo, but rather the success of the patient's treatment and the minimization of material and other costs. Moral issues and dilemmas related to the status of the embryo remained in the background, and respondents often did not seem to have really thought about these aspects in depth during their treatment process. Rational considerations came to the fore in their thinking.

This ethical framework was typically present when we asked the latter about what had caused emotional difficulty or created a dilemma in relation to choosing a procedure or during a procedure, or when respondents thought about going for another IVF cycle. Hormonal stimulation and its side effects were considered a big challenge for patients, who often complained of having insufficient information. Decisions about continuing treatment were partially based on the side-effects of previous treatment, the cost of such treatment, and any stress and failure they had suffered during treatment. Life ethics considerations concerning the embryo did not appear in these accounts about such decisions.

There were only a few cases when our interviewees approached the situation from a

life ethics perspective during their assisted reproductive procedure, even before they had any success with it. These women, while applying an abstract view of embryos as forms of life, also viewed the latter in a personal way, as their children. But whilst a life ethics approach was identifiable for a few women, for an overwhelming majority the medical treatment ethical framework dominated.

There was only one woman who, because of life ethics concerns, asked for a procedure that was different from the usual protocol. She requested to have a small dose of hormones so that she would not have too many surplus embryos, because she wanted all of them transferred. She considered embryos to be human beings right from the beginning of the procedure.

Decisions about freezing embryos during an IVF cycle were also motivated by the practical use of this technology via a medical treatment ethical frame, and not by the abstract moral status of the human embryo. The main reasons behind the choice for freezing were the physical and psychological burdens of hormone treatment. Our respondents often considered the use of frozen embryos for the next IVF cycle to be less stressful:

The frozen one is better, I think, ... because it is implanted within a natural cycle, this frozen embryo, so the body can have a little rest, so it is not like when you get a full hormone treatment. (Sophie)

5.3 Normalization of IVF and a stress on the goal

Interviewees accepted IVF treatment as a necessity, and considered it a normal way to deal with infertility. IVF was often perceived as the only choice.

You can decide on a date... you have practically no other decision, because this is the only way if you want a child. (Tilda)

Respondents had all wanted to try all the possible IVF options before considering any other avenues, such as adoption—as having a child using their own gametes was preferred. They did not think about the fate of the surplus embryos that are the side products of medically assisted procreation, and therefore did not contemplate any alternative artificial reproduction process that could have avoided the problem of unused embryos. They did not ponder solutions that would have resulted in the production of fewer surplus embryos out of ethical considerations—such as having their zygotes frozen or vitrified, or avoiding hormonal stimulation so that less embryos would be produced in the first place, or asking for all embryos to be implanted in the procedure—as all these options would have reduced the chance of success considerably. As our respondents felt that they had only one way to reach the goal that was most important for them, dilemmas concerning surplus embryos were relegated to the background.

According to the accounts of the respondents, the clinics had strongly focused on the success of the transfers. In many clinics, pictures of babies are used as illustrations on the walls. Thus, couples waiting for their treatment are faced with images of others' happiness, maintaining the former's focus on the ultimate goal rather than developing their own views and assessment of such procedures.

Our interviewees revealed that during the procedures they always focused on the goal they wanted to attain. This kind of medical treatment ethics was therefore characterized by strong stress on the end result. We have previously identified the fact that having your

own child is especially highly valued in Hungary (Miettinen & Szalma, 2014; Szalma, 2014). The situation was no different with our interviewees, who felt that they were willing to make even a huge sacrifice to be able to have their own baby:

It did not count then, that this may or may not cost our health—we just wanted to have a baby, at any cost. (Sage) We did not really think this over, because we did not even know what a test tube was, so we did not dwell on it beforehand. We just had one goal: to have a baby, whatever the consequences, so we just jumped in. (Hannah)

5.4 Decisions about surplus embryos in relation to the longer term

Although most decisions were based on the medical model and motivated by the success of IVF treatment, in some cases alternative ethical considerations also arose. Especially characteristic of those who had already had a child as a result of the IVF treatment, but had surplus embryos stored, was the fact that they were concerned about the destiny of their frozen embryos. Many patients were not sure about their reproductive plan (whether they would like to have another child), but they felt that the destruction of their embryos was a choice they could not easily make. Since during each phase of IVF treatment they were concentrating on the next step, they often said that they did not foresee encountering this dilemma at the end of the procedure.

In the accounts, after already having children, one of the most important aspects in decision making about the use of frozen embryos was whether having a sibling would be good for the family (which can be seen as a kind of kinship ethics framework, albeit different from that described in Roberts' 2007 study). In addition, it appeared to be a serious dilemma for respondents whether to expose their bodies and souls to the difficulties of the IVF procedure again (medical treatment framework). Some interviewees explained that, precisely because of the latter, they would be happier to get pregnant spontaneously than go through another IVF cycle with earlier frozen embryos. Postponing difficult decision making by using stored embryos also emerged as a kind of coping strategy.

It was hard again, right in the summer, when I couldn't decide whether to freeze any further, and my indecision wasn't because of the amount of money, but because I didn't know if I wanted another baby at all; and if I did, then when. Now I lean towards wanting to try again. But it was in my thoughts that they were frozen there, and I didn't want it [the freezing process] to stop suddenly. I think it already involves a small beginning life. It's not that if I don't pay, then I am killing them, it's not that drastic. However, I have their fate in my hands, even though I wouldn't necessarily call them people, but somehow the thought that you still have to decide about future people... I had to think a lot about it. That's why—and because I didn't know when I wanted to continue—I took time for myself to make a decision as well. [...] I couldn't decide what to do with the embryos, I can't say I don't need them, but I can't say I need them now. (Sarah)

Some of the interviewees thus expressed views which are more similar to those of life ethics when faced with the situation whether to terminate storage—even if for other decisions during IVF they had used a medical treatment ethics frame. In relation to this choice, they were of the view that the destruction of embryos should possibly be avoided. However, their perspective differed from life ethics in the sense that frozen embryos were not given completely the same moral status as human beings. Two interviewees who we

have earlier discussed used a life ethics perspective throughout their IVF procedure, but also awarded the moral status of a human being to any kind of embryo, frozen or not.

Before starting the procedure and during the first phases of the procedure many of the interviewees had little information about what to expect, and what decisions they would have to make. Not being fully informed, and always focusing on the actual procedures could have meant that patients lost sight of the consequences. They never really thought of other future consequences besides having a successful pregnancy—such as having potentially viable surplus embryos. For many women who have not yet succeeded with the assisted reproductive procedure, having viable embryos at the end of the process that they would not make use of was only a distant possibility. The destruction of these viable embryos then could be postponed for many years if they decided to continue with storage.

Many interviewees thought that donating surplus embryos for research could create meaning from their sacrifice. For some of the interviewees, the development of science was a value in itself. For others, it was a more important point that any solutions developed through this process would be specifically aimed at improving existing in vitro fertilization techniques. In this ethical framework, therefore, the embryo is seen as increasing the chance of helping future patients to succeed with their own IVF treatments.

I supported the idea because this way I can help them make freezing and research more professional. That is all. Nothing more really... (Alexandra)

Research which used embryos as material for non-reproduction-oriented research was less likely to be preferred. This has important ramifications for legal policy as well.

A few respondents felt that they would not be able to donate their surplus embryos to scientific research, exactly because they attributed human life to them. Sandra, for example, spoke of embryos as 'human beings' and therefore rejected the idea of using embryos in scientific research. It should be noted here that she did not have surplus embryos and she first heard of this possibility only during the interview, so she had not been faced with this dilemma caused by the related (emotional) difficulties. It is also interesting that she interpreted embryos abstractly as 'life,' and personally as her own babies:

I would not offer them... they should not play around with our little babies... they are beings, human beings, and really, there is an adult here... kin... [I do not think] anyone would be happy that they are used in research. (Mary)

All of the interviewees rejected the idea that their surplus embryos should be donated to other couples. Different reasons were used to support this conclusion, but most of the latter used the frameworks of ownership ethics and kinship ethics in their arguments.

6 Conclusions

The accounts of interviewees reveal that most of the decisions about embryos were predominantly motivated by interviewees' own interest in the success of treatment, or the desire that the treatment would occur with the least possible difficulty—especially during the IVF procedure itself, before successfully having a child. In order to characterize this type of ethical perspective, we rely on the notion of the 'ethical framework of medical treatment.' One could argue that it is only natural that a woman would be first and foremost interested in her own health and well-being and the success of the fertility treatment

she undergoes, but, as we have argued based on research by Roberts (2007), this should not be taken for granted. In the latter's research other sources of motivation also informed IVF clients' decisions.

We found that interviewees typically viewed embryos differently within the ethical framework of medical treatment than they are viewed from a life ethics approach. While the latter values all embryos highly, and connects every one of them to life (Roberts, 2007), the ethical framework of medical treatment applied by the respondents created some kind of an embryo hierarchy. From this perspective, those embryos that assist women to achieve their goals are considered more valuable and more important.

Therefore, we were able to observe that the interviewees interpreted embryos not in a static and stable way, but constructed them in a malleable and constantly changing way. They spoke of the embryo in different ways, depending on factors such as time (the age of the embryo), space (inside or outside the womb), biological characteristics (is it viable, is it developing), or the perceived role it can play in helping them to reach their goals (birth of a healthy baby). The more time the embryos spent in the womb, the greater the attachment of the women to them.

The interviewees' dynamic view of the embryo sharply contrasted with the core of established legal discourse, which is more static in its construction of the embryo and does not have such a wide variety of changing understandings.

In addition to the dominant ethical framework of medical treatment ethics, several other ethical frameworks emerged in our interviews, primarily related to embryos that remained after a successful pregnancy. One of the by-products of IVF processes is the large mass of residual frozen embryos, some of which are not ever expected to be used. Based on the interviews, it appears that many patients are unaware of this when deciding on the procedure. During the treatments, the patients focus primarily on the given stage of the procedure or on the desired pregnancy goal, and do not think about what will happen after their goal is fulfilled.

When interpreting the results it should be taken into account that they cannot be generalized – not least because of the small sample size and potential selection effect, as those who gave the interviews may differ from those who did not. Another limitation of the research is that we only interviewed women, and we asked them to recall their IVF experiences interviewees retrospectively.

As for the policy implications of our research, we believe that the perspectives of those undergoing IVF should be taken into account when protocols on informed consent are designed and when laws are made regarding in vitro treatment. Based on our study it seems that there is a personal moral space which represents women's dynamic vision of their embryos at different stages of the treatment. This dynamic ethical vision could be taken into account to shape a more individualized version of the informed consent procedure (informed consent is the process of giving information to patients about their treatment, which, among other elements, includes an assessment of potential risks, benefits, and consequences, based on which permission is asked for the treatment, and the former are asked certain decisions in relation to this). In the case of IVF, such decisions can include what happens to embryos. As patients concentrate on the treatment phase they are currently at, and do not look further ahead, it may be a good idea, for example, to ask for informed consent at each different phase so couples can take their experiences into account. Clarifi-

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cation is needed for clinics, researchers, and in the wording of the law in a way that makes it obvious that research on embryos is allowed in Hungary. If research on embryos were more common in Hungary this could help, as our research showed that for some women who engage in IVF being able to donate their surplus embryos to research would help them feel that their suffering was not meaningless.

When the first laws on IVF were adopted, they were not preceded by consultation with consumers of medical services or patients as, understandably, the latter could not yet formulate an opinion about this novel treatment. Therefore, the approach was inevitably technocentric, and based on cutting-edge technologies. Decades after the adoption of the first IVF laws, however, the situation is completely different: it is possible to fine-tune the rules, to take into consideration good ethical practices, and to reflect on the experiences of those who participate in such treatment. This can be regarded as narrative justification for good bioethical practices (Arras, 2017), such as asking for patients' concerns and using non-technical language in informed consent forms. Whenever it is necessary, individual consultations can increase understanding of patients' fears and concerns about their surplus, implanted, or frozen embryos.

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