



Journal of Intercultural Management and Ethics

JIME

ISSN 2601 - 5749, ISSN-L 2601 - 5749

published by

Center for Socio-Economic Studies and Multiculturalism

Iasi, Romania

www.csesm.org

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ETHICAL CONSIDERATIONS IN ASSISTED REPRODUCTIVE TECHNOLOGY

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Abstract

Our study aims to summarize the evidence on the ethical considerations of assisted human reproduction procedures and see what these techniques look like through the eyes of the women who experience them. Our research comprises the experiences of 50 women who used such technologies to have a child and detailed their related experiences (i.e., "If you have already resorted to assisted human reproduction treatments, please detail the experience"). The participants' answers, which were consistent with the previous literature, among the difficulties they faced, the bad patient-doctor relationship (the right to life and equal treatment), the multitude of contradictory information in the public space (the right to be informed), the feeling that experiments are being done on the patient's body (the right to be advised), medical errors that led to pregnancy loss (the right to life), the feeling that private clinics are just businesses that have to make money, but not to take into account the patient's life (marketing), and the high economic costs (economy) were among the most frequent. Our results concluded that decision-making concerning assisted reproductive technologies cannot be based only on clinical and economic considerations but also require considering a series of ethical principles, social norms, and religious beliefs.

Keywords: fertilization in vitro, assisted reproduction technologies, ethics

Introduction

Having a child is a goal of many women or couples. Almost 1 in 7 couples can't have a naturally conceived baby, depending on their medical condition. Because of this, medical technics have been developing in the last decades, giving these couples or women chances to become parents. Many will avail of Assisted Reproductive Technology [ART] to achieve this goal. This decision is often made due to various social influences, seeing childlessness as "abnormal" and stigmatizing infertility (Nadimpally & Venkatachalam, 2016). At the same time, private infertility care clinics capitalize on the existing cultural norms and values, through marketing campaigns, with the aim, above all, to increase their turnover (Mukherjee & Nadimpally, 2006; Nadimpally & Venkatachalam, 2016).

ARTs are a group of reproductive technologies which assist conception and pregnancy. The technologies used for assisting reproduction range from simple or 'low-tech' methods like artificial insemination to 'high-tech' methods such as In Vitro Fertilization [IVF] in all its variation (Sama, 2006, as cited in Mukherjee & Nadimpally, 2006). Techniques that ARTs refer to, are: (a) artificial insemination (AI); (b) in vitro fertilization (IVF); (c) intracytoplasmic sperm injection (ICSI); (d) gamete intrafallopian tube transfer (GIFT) and (e) zygote intrafallopian tube transfer (ZIFT). However, these techniques raise several ethical issues about which Edwards (Edwards & Sharpe, 1971; Edwards, 1974), the pioneer of ART, said it is important to resolve. Among the areas that address the ethical issues involved in ART are but are not limited to religious beliefs, genetic medicine, the right to life (even a good life), the financial field, the right to a family, the right to privacy and marketing.

In terms of the right to a good life, ESHRE's Task Force Ethics and Law (2007) has defended a 'reasonable welfare standard,' according to which fertility professionals should refrain from participating in reproduction only in cases where there would be a high risk that the future child would have a seriously diminished quality of life. The need for previously psychological and social screening of intended parents was mentioned. Also, regarding the child's life, among the ethical questions raised by Shalev et al. (2016) notes the question of whether or not children have the right to know the identity of their genetic progenitors and whether or not they have the right to know the identity of their gestational mother.

The same authors mention that Inter-country, Medically Assisted Reproduction [IMAR] transforms reproductive relations' personal and intimate nature into contractual and labor relations. Market-driven reproductive technology may impact the future of humanity and human nature itself. The deep concerns are about the moral limits of markets, given the foreseeable technological developments that would allow genetic selection and modification of human embryos (Shalev et al., 2016).

Also, regarding the "contractual" relation, there are many debates on the commercialization of IVF. The most significant worries are the reimbursement of gamete donors (egg donors in particular), the selling of embryos, and the use of IVF for commercial surrogacy purposes. Ethical questions often raised in the debate include fairness, the possible exploitation of need and hope, genuinely informed consent, and the many components of marketing ethics (Asplund, 2020).

Another critical issue in the ethics field is the communication between clinical genetics, IVF teams, and patients, namely the lack of information provided to intended parents about the preconception and prenatal genomic testing (preimplantation genetic diagnosis (PGD) and preimplantation genetic screening (PGS) (Harper et al., 2013). Truly informed consent is needed in all the stages of the procedure – before, during, and after. Equal access to medically assisted reproduction in Europe and beyond was mentioned as mandatory by Harper et al. (2013). This would involve cheaper, affordable treatments or even free of charge.

Regarding the right to a family, there are three directions of interest: the single woman case (Záchia et al., 2011), same-sex couples (Asplund, 2020), and solo reproduction within Vitro-created gametes (Cutas & Smajdor, 2017). All three cases differ in practice depending on the laws of each country (Kooli, 2020; Asplund, 2020). After we summarize the evidence on the ethical considerations of assisted human reproduction procedures, we wanted to see what these techniques look like through the eyes of women who experience them.

Study design, measurement tools, and the features of the participants

This study is based on an online sample. Data were collected between April and June 2021 through Google Forms. Participation in the survey was voluntary and anonymous, and a participation agreement was obtained from all participants before data collection. The main selection criteria for the study are female gender. This study is part of a more extensive study, which involved a more significant number of participants. This study is part of a more comprehensive study, which involved a more substantial number of participants. For the data analysis related to this research, we selected the participants who chose to share their experience with ART, a total of 50 women. They all were asked to answer the question: "If you have already resorted to assisted human reproduction treatments, please detail the experience here."

The age of our participants ranged from 22 to 41, with a mean age of 33.48 (SD = 4.05). Most of them come from urban areas (74%), are orthodox (88%), finished their master's studies (54%), work as employees in executive positions (58%), are married (90%),

are childless (80%), not pregnant (88%) and still want an (another) baby (92%). Only three of them said they had overcome infertility and conceived naturally.

Overview of statistical analysis

The data analysis was performed with the help of Nvivo 12, because it consisted of qualitative data. The principle according to which the qualitative data was grouped was the following: the elements placed in the same group must be as similar as possible to each other and as different as possible from the elements identified in other groups. The literature mentions five methods for qualitative coding data: open coding (sometimes called conceptual or thematic coding), axial coding, selective coding, accurate coding, and interpretive coding. For our study, we will use open and axial coding. In open coding we formed the initial categories without making a priori assumptions about what kind of categories could be identified. After that, we used axial coding for grouping the previous codes into different themes.

The main themes that emerged, after axial coding, were the following:

- a) the underlying causes of negative emotional response
- b) coping strategies
- c) the magnitude of the desire to become a mother
- d) the effect of treatment on the emotional response
- e) the needs these women have.

A subcategory of the underlying causes of negative emotional reactions was the ethical issues that women faced during the procedures. The codes are detailed in the Table 1.

Table 1. Ethical issues subthemes

Name	N
Business as aim (marketing)	4
Defective patient-doctor relation (medical errors, lack of information)	9
High costs	20
Lack of information in public space	3
Public health services problems	6

Results

As seen in Table 1., among the difficulties mentioned by the women involved in our research, who went through an ART experience (n=50), we say the terrible patient-doctor relationship and the medical errors, the multitude of information in the public space that is contradictory, the feeling that experiments are being done on the patient's body and the risks of the treatment, the feeling that private clinics are just businesses that have to make money, but not to take into account the patient's life. Last but not least, the costs of these techniques seem to be a real problem, given that treatments paid for by public health services are hard to access.

Regarding the doctor-patient relationship, we detail below some of the shared experiences:

30 years-old, married, childless: *“I lost my pregnancy due to a medical error. I was scared at first but brave, thinking that this was the only way to have a child, but the medical mistake disappointed me enormously. I still suffer, and it is unfair. Doctors should pay more attention to the fact that such a medical error can lead to suicide or even serious mental health problems.”*

23 years-old, married, childless *“Our chances were 100% and 0% simultaneously; unfortunately, choosing an untrained doctor in a hurry made the 0% chance to win.”*

34 years-old, in a stable relationship, childless: “(...) it's hard to find a good doctor to take an interest in.”

37 years-old, married, childless: “(...) my husband has been facing a bacterium in the sperm culture for eight months, and until he made antibiotic injections, he did not escape, treatment finally given by a very old doctor (other than our infertility doctor).”

36 years-old, married, childless: “Slightly frustrated by the disorganization/lack of information from the clinic/doctor I will have IVF with.”

Regarding the feeling that experiments are being done on the patient's body and the risks of the treatment, four of our participants told us:

35 years-old, married, childless: “Now, with IVF already done, I no longer have the strength to understand why I can't transfer any embryos: the stimulation brought me an endometrial polyp that I didn't expect; I thought I would be pregnant by now.”

37 years-old, married, childless: “For only four years, I have been struggling with IVF, and I have faced many unpleasant situations. I have low immunity; I take the bacteria continuously; my husband has been facing a bacterium in the sperm culture for eight months....”

35 years-old, married, childless: “(...) but embryo transfers remain to be performed, which are still delayed due to problems with hormonal stimulation.”

23 years-old, married, childless: “As the procedure to follow is difficult for me as a woman mentally and physically because I had some problems that appeared as a surprise.”

Considering the ethical marketing issues, one of our participants, a childless, 30 years-old woman told us “... (the doctors and the clinics must) ... give up the idea of a "band." I understand that a private clinic is a business like a watch store, but it's about the patient's life!"; “Many doctors call you at their private practice, of course, for the money.”

Regarding the usefulness of advertising, one of the participants, a childless, 26 years-old woman said: “I think it should be more publicized because not everyone knows and can't understand. I had co-workers who told me I didn't know when to have sex so that I couldn't get pregnant.”

Furthermore, almost half of the participants complained about the costs of these procedures (20 out of 50 mentioned this issue). They talked about how much the system cost them, but they also spoke about the consequences of these high costs on their emotional health.

37 years-old, married, childless: “It's different every time; the higher costs that bring you to your knees matter greatly. There are countries where you can do these procedures at no cost, a situation that helps you mentally for a long time.”. She also said that, “unfortunately, money is a real problem. In vain, you get along well with your psyche and motivate yourself if you don't have the money.”, and “I am convinced that there are many girls who want and cannot even dream of such procedures due to the material situation.”

23 years-old, married, childless: “As for costs, I can say that these procedures cost a lot, considering our salaries.”

39 years-old, in a stable relationship, childless: “Very high costs, beyond our financial possibilities - about 7000 euros spent (analysis, investigations, oocytes, procedure, roads, accommodation).”

23 years-old, married, childless: “The money was borrowed from the bank.”

31 years-old, married, mother of one: “It was a difficult experience, which required much financial effort.”

Another fundamental problem is that ART treatments are not fully covered under the public health service, and this fact makes them inaccessible to many women or couples, a fact confirmed by our participants: *“I was disappointed by the high costs and the minimal support offered by public health service.”* (31-year old female participant). *“The public health service does not help you. You also pay for the HIV or pap smear test.”* The waiting periods for an appointment are also an important issue. One participant (female, childless, 37 years-old) told us that *“Plus, you've been waiting for months for an appointment at the state hospital. There are even four months of waiting for the first appointment with an infertility doctor, which is not ok. After the tests (many tests must be done on certain days of the menstrual cycle), wait a few months for interpretation, and if there is a problem with the tests, start treatment and wait months until the next appointment. It's cruel.”*

All this information helps us get an overview of the impact of the ethical implications of ARTs on every woman or couple who wants to become a parent.

Discussion

Undoubtedly, pregnancy is the ultimate desire of all women and couples who use such techniques, but no one anticipates the problems that may arise. As we can see, even if the ethical issues weren't so often mentioned, as were the feelings they faced during these experiences, they are an essential aspect of becoming a mother. These problems bring emotional instability and can even lead to abandoning the dream of becoming a parent.

Given the side effects impact on patients, we believe the physician must discuss the risks of all medicines and treatment with the patient. At the same time, perhaps a set of written materials, along with or in the form of informed consent, offered to the patient would help him make many better-informed decisions. This way, the problems related to ethics in the patient-doctor relationship can be reduced. These ideas are also supported by previous research (Shanner & Nisker, 2001; Etchells et al., 1996).

It also seems that fair marketing is not incomprehensible to people interested in assisted human reproduction techniques. However, market values may not be the proper basis for raising families, as Patrizio et al. (2022) concluded. It is entirely unethical to take advantage of their willingness to become parents and speculate on social norms (Nadimpally & Venkatachalam, 2016; Mukherjee & Nadimpally, 2006). Returning to the previous idea, it is essential that people who turn to the services of specialized clinics feel safe, meaningful, and properly cared for. When it comes to people's lives, women/couples should be seen more than those customers who buy a product that leads to an increase in the company's turnover; empathy is essential in such a business.

The idea of Harper et al. (2013) about the need for equal access to medically assisted reproduction is supported by our study. Cheaper, affordable, or even free treatments would make the ART road easier. Caring about the amount of money needed for each stage of treatment can affect a woman's emotional health, so it must be considered financial support for the couples/women who cannot become pregnant naturally.

Conclusion

ARTs are more than drugs, tests, and procedures. They are also about feeling safe in your relationship with your doctor, being well informed, receiving financial support, and feeling that your health is paramount on this path that is very difficult to deal with emotionally. It seems that decision-making concerning IVF cannot be based only on clinical and economic considerations. Ethical principles, social norms, political relations, and religious beliefs are mandatory. Legal harmonization in ART worldwide and even access to treatment for infertility are required to avoid ethical issues.

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