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Bioethics in the adversities of access to infertility treatment

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Abstract

Infertile couples face barriers in access to specialized medical care, leading to a movement that seeks equality in access to infertility treatments. Identifying the ethical issues involved and understanding how discussions about justice occur in the provision of medical infertility treatment is important. A literature review was conducted using the Web of Science, PubMed, and Google Scholar databases. In general, articles showed that most countries do not meet ethical requirements of distributive justice. Articles pointed to barriers to access and resistance that exists in accepting infertility as a health problem. They also demonstrated the suffering caused by infertility and the urgency of putting ethical concepts into practice so that solutions may be adopted. In conclusion, an ethical debate that achieves provision of well-being for all can improve health and the feeling of justice on the part of health professionals and policy makers.

Keywords: Access to health. Bioethics. Infertility. Human reproduction. Reproductive rights.

Resumo

Bioética nas adversidades do acesso ao tratamento de infertilidade

Casais inférteis enfrentam barreiras no acesso a cuidados médicos especializados, levando a um movimento que busca a igualdade no acesso a tratamentos de infertilidade. Identificar as questões éticas envolvidas e entender como ocorrem as discussões sobre justiça na prestação de tratamento médico de infertilidade é importante. Uma revisão da literatura foi realizada usando as bases de dados Web of Science, PubMed e Google Scholar. Em geral, os artigos mostraram que a maioria dos países não atende aos requisitos éticos de justiça distributiva. Os artigos apontaram barreiras para o acesso e resistência que existem na aceitação da infertilidade como um problema de saúde. Demonstraram, ainda, o sofrimento causado pela infertilidade e a urgência de colocar em prática conceitos éticos para que soluções possam ser adotadas. Um debate ético que alcance a provisão de bem-estar para todos pode melhorar a saúde e o sentimento de justiça por parte dos profissionais de saúde e formuladores de políticas.

Palavras-chave: Acesso à saúde. Bioética. Infertilidade. Reprodução humana. Direitos reprodutivos.

Resumen

Bioética en las adversidades del acceso al tratamiento de infertilidad

Las parejas infértiles se enfrentan a obstáculos para acceder a cuidados médicos especializados, lo que ha dado lugar a un movimiento que busca la igualdad de acceso a los tratamientos de la infertilidad. Es importante identificar las cuestiones éticas implicadas y comprender cómo se producen los debates sobre la justicia en la prestación de tratamientos médicos de la infertilidad. Se realizó una revisión bibliográfica utilizando las bases de datos Web of Science, PubMed y Google Scholar. En general, los artículos mostraron que la mayoría de los países no cumplen los requisitos éticos de la justicia distributiva. Los artículos señalaban las barreras de acceso y la resistencia a aceptar la infertilidad como un problema de salud. También demostraron el sufrimiento causado por la infertilidad y la urgencia de poner en práctica conceptos éticos para poder adoptar soluciones. Un debate ético que consiga proporcionar bienestar a todos puede mejorar la salud y el sentido de la justicia por parte de los profesionales sanitarios y los formuladores de políticas.

Palabras clave: Acceso a la salud. Bioética. Esterilidad. Reproducción humana. Derechos reproductivos.

Research

The authors declare no conflict of interest.

Since 2009, the World Health Organization (WHO) classifies infertility as a disease and a global public health problem [1] that can affect approximately 15% of couples in their reproductive age [2], generating unexpected distress and stress [3]. Worldwide, couples face several barriers or impediments to access specialized medical care and fertility treatments [4], leading to discussions and mobilizations that seek distributive justice and equal access to medical centers and assisted human reproduction treatments.

Several countries lack a specific law on the right to infertility treatment; however, the concept of reproductive justice is based on four fundamental principles, one of which provides for the right to all to have children [5]. An article published by the European Society for Human Reproduction and Embryology (ESHRE) in 2008 underlines that the right to equal access to basic health care is essential to ensure everyone has a range of opportunities for medical care, regardless of their income or financial means [6]. The article also states that the most important factor causing disparity in access to health care is individuals' ability to pay [6].

Medical conduct based on ethical principles stands out: respect for autonomy of choice, beneficence, non-maleficence and, especially in this context, justice [7]. The principle of justice assures patients fair and equitable access to the available health services [8]. Moreover, ethics and biolaw must follow advances in reproductive medicine to enable humanist conduct and respect for rights. Ethics and biolaw recalls that treatment in the health area should override any lucrative purpose and prioritize well-being [9].

In Brazil, the 1988 Federal Constitution declares the fundamental rights of all Brazilians and the basic principles of access to health rights, especially in art. 1, III and art.196, which refer to social policies, human dignity and the promotion of health as a right of all and duty of the State, respectively, guaranteeing equal access to health services and social justice [10]. Moreover, the International Conference on Population and Development (ICPD), held in Cairo in 1994, recognized that providing assisted reproduction treatments for infertile couples in countries with few resources is a reproductive right, in addition to recognizing reproductive rights as human rights [11,12].

However, despite millions of successful cases of assisted reproduction treatment and their medical and technological evolution, the impossibility or difficulty in access experienced by many infertile couples, especially in developing countries or poorer regions, is noteworthy [11]. Thus, it appears that despite the recognition, even if still insufficient, of the right to reproductive health and family planning, many couples still face the lack of opportunity—whether of financial, social, communication or location nature—to access infertility treatment and become parents.

In investigating the different circumstances in which populations live, a study published in 2017 confirmed the need to propose tools to reach quality health services considering the resources available in a specific community. Besides, governments must assume the difficulty in providing the right to the same health status for all given the different conjunctures, such as family, social and economic conditions [13].

Promoting the universal right of access to health care is still a challenge and it is unfeasible to idealize the right to infertility treatment services for all individuals without observing the particularities of a community and without involving a bioethical content, as the fundamental right to procreation is based on solid moral and ethical concepts [14]. Thus, it becomes of paramount importance to identify the ethical issues involved and to understand how discussions and awareness about the fairness of providing medical care and treatment opportunities to infertile couples around the world are evolving.

Method

The bibliographic search was conducted from April to June 2023, on the topic "bioethics in the adversities of access to assisted human reproduction," using the Web of Science, PubMed and Google Scholar databases, book chapters and websites of relevant organizations and societies. The Health Sciences Descriptors (DeCS) used were bioethics, infertility, health disparity, health inequity, health rights and reproductive health services. The inclusion criteria consisted of articles published after 1980 in English or Portuguese.

Literature review

The main point of this study, in addition to praising the importance of listing the ethical issues to overcoming the adversities of medical access encountered by people with infertility, is to expose the need for keeping the ethical discussion updated and strengthened.

Studies claim that infertility incidence has been increasing mostly in developing countries [4], reaching 30% infertility rate in some populations [15]. High infertility prevalence in certain regions may suggest lifestyle and environmental problems that affect the fertility of the local population, and/or disparities in access to medical specialists [16].

Surveying how individuals in developed and developing countries access infertility treatments show that most countries do not comply with the ethical requirement of distributive justice and do not offer public funding for infertility treatment. However, even in countries like the United Kingdom, where medical treatment is funded by the State and available on the National Health Service (NHS) [17], since policy makers consider infertility a disease, though some discourses disagree with this position [18], and arguments that see infertility only as a failure reinforced by social and cultural pressure to have children [19]. But many articles attest that for many women and men infertility is not simply about the impossibility of having children; rather, it indicates a disrupted life project, causing psychological suffering and a feeling of inability to achieve primary life expectancy [20-22].

The *Universal Declaration on Bioethics and Human Rights* proclaims as one of its objectives *to promote equitable access to medical, scientific and technological developments as well as the greatest possible flow and the rapid sharing of knowledge concerning those developments and the sharing of benefits, with particular attention to the needs of developing countries* [23]. The *Universal Declaration of Human Rights* states, in art. 16.1, that *men and women of legal age, without any limitation due to race, nationality or religion, have the right to marry and to found a family*, while art. 25 includes the right to medical assistance [24]. Infertility treatment is thus considered a human rights issue, but in practice its inclusion as mandatory coverage often depends on justifications [25].

Additionally, studies point out unequal access to assisted reproduction treatments or even to the first consultation with a fertility specialist for reasons such as (1) location: less developed countries or states, (2) financial: public health does not offer more expensive treatments, (3) racial and ethnic disparities [15,26], and (4) lack of disclosure or communication: couples remain ignorant of the health problem and the possibility of treatment. Hence, assisted reproduction treatment is absent or inaccessible for many infertile couples around the world.

A 2021 article states that attempts to promote equitable access to medical services and infertility treatments are not few, including actions by the United Nations (UN) [24], WHO and a declaration by the US Center for Disease Control (CDC) placing the diagnosis and treatment of infertility as a national public health priority [27]. However, treatments for infertility are often interpreted as being elective, reinforced by the resistance in assuming infertility as a health problem.

Evidently, due to advances in reproductive medicine that enable couples or an individual to have children, many lines of thought do not consider all causes of infertility as a disease. Maung claims that this argument is important for a medical, ethical, and philosophical debate, as it indicates that the problem with infertility is its heterogeneous categorization and disagreements about which types of infertility qualify as a disease [18].

In contrast to resistance, Rutstein and Iqbal showed how most infertility cases stem from the inability to conceive a healthy baby when analyzing information from 47 demographic and health surveys conducted in developing countries and estimated that, in 2002, more than 186 million married women of reproductive age had primary or secondary infertility [28]. In addition to the importance of general well-being for one's health, well-being can even be associated with the realization of motherhood and/or fatherhood, numerous other causes can lead couples to need assisted reproduction treatment such as trying to avoid the birth of a child with a specific genetic disease [6].

Research

Organizations and medical professionals make efforts to fulfill the rights of infertile couples and reduce barriers to access by extending low-cost fertilization treatments to low-resource settings [16]. In Europe and North America, for example, the low-cost IVF–LCIVF movement is , based on the definition of reproductive justice, seeks to overcome barriers and bring low-cost fertilization treatments to regions with limited resources [4]. Nonetheless, public policies should assume infertility as a public health problem and seek financial resources within budgetary allocations or public-private partnerships to mitigate the lack of accessibility. Nunes and collaborators indicate that the power of international institutions and a global ethical conscience can be a starting point to promote the universal right of access to quality health in countries that prioritize other social needs [13].

Studies point out that the debate on offering public funding to treat infertility follows a conservative line. Although it can be rationally understood, the resistant pretext to providing specialized medical care and treatment financed by the state or covered by medical agreements and health insurance clashes against ethical principles, under which every individual, without limitation of race, nationality, religion or socioeconomic level deserves and has the right to marry and found a family [2].

For Pennings and Ombelet, a fundamental step towards making a health system with equal access viable is assuming that it is best to adopt the cost-effectiveness criterion [29]. According to Brown and collaborators, the strategy of offering public infertility treatment involves an ethical discussion given all the harm that people who want to have children and face difficulties in achieving this life project endure, such as suffering, frustration, anguish, social and cultural adversities [30].

Thus, an important step towards offering access to all who need treatment is to accept that infertility is a disease as it also impacts one's well-being. But the ethical discussion still needs to be expanded. In addition to admitting that infertility is a disease, an in-depth understanding of what the access barriers are allows knowing the details and drives the search for alternatives and solutions to provide basic health care to all.

ESHRE indicates that even in countries that offer reimbursement for infertility treatment through the public system or insurance coverage, low-income groups and those with low education make significantly less use of health services, clarifying the importance of educating the population and raising awareness on fertility care and treatment options [6]. Additionally, ensuring equitable access to infertility assessment, treatment, and care is seen to depend on the engagement of health professionals and policy makers [27].

Most current data show that black women, when compared with white women, have fewer opportunities to be evaluated and treated for infertility, and that people of lower socioeconomic status seek less infertility services [31]. Ombelet and collaborators note that even the implementation of low-cost treatments is unlikely to make these accessible to all, and that for men and women living in extreme poverty, the ideal would be socio-political interventions to improve their economic situation [32].

Despite identifying possible barriers to access, we still face great difficulty in interpreting the causes in a manner that brings efficient solutions. Corroborating this, Perritt and Eugene state that access inequalities are poorly understood and suggest racism and economic contrast as likely causes [27].

Bahamondes and Makuch cited an analysis of population surveys that estimated the prevalence of infertility from 3.5 to 16.7% in developing countries and from 6.9 to 9.3% in developed countries [33]. Accordingly, this literature review argues that infertility affects individuals with different conditions worldwide, but much emphasis is placed on the fact that the preventable causes of infertility are different between some groups, therefore different actions may be necessary. For example, a study noted that the poorest population in developing countries is prone to infertility due to poverty, low education, early initiation of sexual activities, unsafe abortion and lack of counseling services and medical care [34], thus preventive public health policies and better assistance to this group would already have a positive effect on reducing the incidence of infertility.

Research

However, avoidable causes of infertility and the search for treatment by economically stable individuals can be justified by the postponement of motherhood to prioritize professional achievement or financial stability. In many Western countries, women try to conceive their first child after achieving other goals in life, when fertility tends to decline [35]. Additionally, cultural and environmental factors interfere with fertility and differ between regions and countries [36].

Thus, although the ethical debate should have the same primary objective in designing distributive justice, it could employ different approaches considering different scenarios to then achieve equity of access. In favor of this premise, White and collaborators raise the issue of sociocultural barriers, indicating language obstacles, communication elements, notions of privacy and prejudices about health care [37]. Nonetheless, by recognizing the magnitude of the suffering that infertility causes in people's lives we underline the urgency of raising awareness and of putting ethical concepts into practice so that solutions are adopted by health professionals and politicians. As Nunes and colleagues argue, it is important to strive for a healthier, more balanced and productive society. To achieve this, global efforts are necessary to implement human rights faster, with the right of access to health being considered a priority, even if it still depends on citizen solidarity to be enjoyed [13].

Final considerations

From this literature review, overcoming the barriers to accessing infertility treatments depends on a comprehensive and continuous ethical approach. In addition to major difficulties in access, such as financial, social and racial issues, and location, there are differences in considering infertility a disease, on the costs of treatment financed by the State, and the discussion on offering infertility treatment to couples under extreme poverty.

Our analysis showed that autonomy and justice are the ethical principles most involved in this discussion, which has led to an ethical debate concerning the quality of life conditions, expectations and consequences on people's lives in different parts of the world. It becomes clear that globally, and not only in developing countries, measures must be adopted for the fulfillment of human rights, prioritizing health care as informed by the context of each nation or country location.

Finally, in addition to political stability, counseling, availability of low-cost treatment options and a basic medical infrastructure, support for couples seeking to achieve maternity and/or paternity can be the starting point of an ethical debate towards offering well-being to all individuals, since providing health is also related to the feeling of justice and user embracement on the part of health professionals and policy makers.

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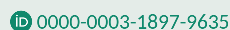 0000-0003-1897-9635

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Participation of the authors

Drauzio Oppenheimer contributed to the study design, bibliographic search, manuscript drafting and approval of final version for submission. Christiane Peres Caldas contributed to the study design, discussion of the literature review, manuscript correction and approval of final version for submission. Rui Nunes contributed to the study design, discussion of the literature review, manuscript correction and approval of final version for submission.

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