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A BUSCA PELO PRINCÍPIO DE JUSTIÇA PARA CASAIS INFÉRTEIS: CARACTERIZAÇÃO DA POPULAÇÃO BRASILEIRA E DISCUSSÃO BIOÉTICA

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Tese apresentada à Universidade do Porto para obtenção do Título de Doutor em Bioética.

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“Ninguém escapa ao sonho de voar, de ultrapassar os limites do espaço onde nasceu, de ver novos lugares e novas gentes. Mas saber ver em cada coisa, em cada pessoa, aquele algo que a define como especial, um objeto singular, um amigo, é fundamental. Navegar é preciso, reconhecer o valor das coisas e das pessoas, é mais preciso ainda.”

Antoine Saint-Exupéry

Resumo

Introdução: A infertilidade, considerada um problema de saúde pública global cada vez mais prevalente, afeta aproximadamente 15% dos casais em idade reprodutiva. Em muitos países, a saúde reprodutiva é negligenciada. Vivenciar a infertilidade e a pressão social por ter filhos tem um efeito emocional devastador, causando sofrimento e impactando negativamente a qualidade de vida. Esta tese visa abordar as dificuldades enfrentadas pelos casais inférteis no acesso aos tratamentos de infertilidade nos países em desenvolvimento, com ênfase no princípio da justiça. Destaca-se a necessidade de uma discussão ética sobre os direitos reprodutivos de uma maneira justa e igualitária. **Método:** Estudo observacional transversal, multicêntrico, realizado por meio de levantamento bibliográfico e aplicação de questionário on-line a casais que procuraram atendimento médico em uma clínica no interior do Estdo de Minas Gerais e em uma Clínica de Reprodução Assitida na cidade de São Paulo (SP). Foram seguidas as etapas: Levantamento de dados, elaboração e validação de questionário, aplicação de questionário e análise estatística dos dados coletados. **Resultados:** A tese resultou em quatro artigos científicos: (1) Access to infertility care in Brazil: Validation of a questionnaire for a bioethical discussion; (2) Bioethics in the adversities of access to infertility treatment; (3) Quality of life in infertile patients in Brazil: religious spirituality as a coping mechanism; e (4) The search for the principle of justice for infertile couples: Characterization of the Brazilian population and bioethical discussion. Os resultados indicaram que a infertilidade impacta negativamente na qualidade de vida dos pacientes, que frequentemente recorrem à religiosidade e espiritualidade como mecanismo de enfrentamento. No Brasil, assim como em outros países em desenvolvimento, a principal barreira de acesso aos tratamentos de reprodução assistida é a financeira, devido aos custos elevados dos tratamentos. Há uma dificuldade de acesso a serviços e profissionais especializados e não e existe políticas de saúde pública para a prevenção da infertilidade.
Conclusão: Existem barreiras e desigualdades no acesso aos tratamentos de reprodução assistida para os pacientes com infertilidade, especialmente nos países em desenvolvimento. Estas barreiras incluem questões financeiras e a falta de acesso a serviços especializados. Há importantes princípios e embates éticos envolvidos na discussão sobre os direitos reprodutivos, que não são tratados de maneira equitativa e autônoma. É necessário clarear as questões éticas que violam o princípio da justiça, particularmente para os grupos mais vulneráveis. A educação pública e a sensibilização dos decisores políticos são fundamentais para promover o acesso justo e igualitário às tecnologias reprodutivas. Esta tese enfatiza a importância de um debate contínuo sobre a ética e justiça na saúde reprodutiva, visando a implementação de políticas que garantam o bem-estar e os direitos reprodutivos de todos os indivíduos.

Palavras-chave: Bioética; infertilidade; princípio da justiça; reprodução assistida.

Abstract

Introduction: Infertility, considered an increasingly prevalent global public health problem, affects around 15% of couples of reproductive age. In many countries, infertility is neglected. Living with infertility and the social pressure to have children has a devastating emotional effect, causing suffering and negatively impacting quality of life. This thesis set out to describe the difficulties infertile couples have in the access to infertility treatment in developing countries, with an emphasis on the principle of justice. The need for ethical discussions on reproductive rights in a fair and egalitarian way is especially discussed.**Method:** A cross-sectional, multicenter observational study, carried out through a bibliographical survey and application of an online questionnaire to couples who sought medical care at the a clinic in the interior of the state of Minas Gerais and at an Assisted Reproduction Clinic in the city of São Paulo (SP. The following steps were followed: Data collection, preparation, and validation of a questionnaire, application of a questionnaire and statistical analysis of the data collected. **Results**: The study resulted in four scientific articles: (1) Access to infertility care in Brazil: Validation of a questionnaire for a bioethical discussion; (2) Bioethics in the adversities of access to infertility treatment; (3) Quality of life in infertile patients in Brazil: religious spirituality as a coping mechanism; and (4) The search for the principle of justice for infertile couples: Characterization of the Brazilian population and bioethical discussion. The results indicated that infertility negatively impacts patients' quality of life, who frequently resort to religion and spirituality as a coping mechanism. In Brazil, as in other developing countries, the main barrier to assisted reproductive treatments is financial, due to high treatment costs. There is difficulty in accessing specialized professional services, and there are no public health policies in effect to prevent infertility. **Conclusion**: There are barriers and inequality in access to assisted reproductive treatments in infertile couples, especially in developing countries. These barriers include financial issues, as well as lack of access to specialized services. There are important principles and ethical debates involved in discussions of reproductive rights, which are not treated in an equative and autonomous manner. Ethical issues should be clarified as to when the principle of justice is not followed, particularly in vulnerable groups of individuals. Public education and bringing awareness to policy-makers are fundamental in providing just and egalitarian access to reproductive technologies. This thesis emphasizes the importance of a continuous debate on ethics and justice in reproductive health, aiming at implementing policies that promote well-being and reproductive rights for all individuals.

Keywords: Assisted reproduction treatment; bioethics; infertility; justice; principle of justice.

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1. Introdução

A infertilidade, já reconhecida pela Organização Mundial da Saúde (OMS) como uma doença e considerada um problema de saúde pública global, afeta aproximadamente 15% dos casais em idade reprodutiva **[1]** e aflige diretamente o bem-estar físico e psicológico dos pacientes **[2]**. É importante destacar que o desejo de ter filhos e compor uma família é constituinte do instinto humano e, sob esta premissa, além das adversidades enfrentadas por alguns casais para alcançar a paternidade e/ou maternidade, a infertilidade tem um efeito potencialmente devastador para numerosos casais, levando a efeitos emocionais negativos e impactando vários aspectos da vida conjugal **[3]**.

Podemos identificar diversos direitos relacionados à reprodução e à saúde reprodutiva. Tais direitos são essenciais para garantir a dignidade humana e promover o acesso equitativo às políticas de saúde pública:

O **direito de ter filhos** é um direito básico intrinsecamente ligado à dignidade humana e à capacidade de procriação. Esse direito envolve não apenas a capacidade biológica de ter filhos, mas também o acesso a tecnologias que permitam a procriação. É um aspecto central dos direitos reprodutivos, afetando diretamente a saúde reprodutiva e os direitos familiares. Estudos destacam a importância desse direito no contexto da bioética, ressaltando seu papel crucial na promoção da equidade e justiça social **[4]**.

O **direito à saúde reprodutiva** abrange todos os aspectos relacionados ao sistema reprodutivo e seus processos. Esse direito inclui a educação sexual, o acesso a cuidados de saúde reprodutiva, a prevenção e o tratamento de doenças, e o apoio para decisões informadas sobre reprodução. É necessário enfatizar a necessidade de políticas públicas que garantam esses direitos, promovendo o bem-estar e a saúde integral dos indivíduos **[5]**.

O **direito à saúde reprodutiva e ao planejamento familiar** é uma expansão do direito à saúde reprodutiva que inclui especificamente o planejamento familiar. Esse direito garante o acesso a métodos contraceptivos, serviços de aconselhamento e informações que permitem a escolha livre e responsável sobre ter ou não filhos, e quando tê-los. O planejamento familiar é essencial para a autonomia reprodutiva e para a promoção da saúde e bem-estar das famílias **[6]**.

O **direito de acesso à reprodução assistida** é um direito específico dentro do direito à saúde reprodutiva, focado no acesso a tecnologias de reprodução assistida. Isso inclui tratamentos como fertilização in vitro, inseminação artificial e outras tecnologias que auxiliam a reprodução. Este direito aponta para as implicações éticas, financeiras e legislativas desse direito, destacando a importância de políticas que assegurem o acesso equitativo e sem discriminação **[7]**.

O **direito de casar e constituir família** é um direito humano básico reconhecido em várias convenções internacionais, incluindo a Declaração Universal dos Direitos Humanos. Esse direito envolve a liberdade de escolher um parceiro, casar-se e formar uma família, englobando tanto aspectos de união legal quanto de procriação. A bioética valoriza esse direito como fundamental para a estrutura social e a realização pessoal dos indivíduos **[6]**.

Após clarificar os diversos direitos, é importante centrar a análise no "direito de acesso à reprodução assistida", pois este é o ponto central da tese. A análise desse direito abrange tanto implicações éticas quanto práticas. Do ponto de vista ético, a justiça distributiva destaca-se como um princípio fundamental, envolvendo a distribuição justa dos recursos médicos e o acesso igualitário às tecnologias de reprodução assistida, independentemente de condições socioeconômicas **[8]**. A autonomia é outro aspecto crucial, respeitando a capacidade dos indivíduos de tomar decisões informadas sobre o uso de tecnologias de reprodução assistida **[9]**. Além disso, os princípios de beneficência e não-maleficência asseguram que os tratamentos sejam realizados com a intenção de beneficiar o paciente, sem causar danos **[10]**.

No âmbito das implicações práticas, é necessário considerar as barreiras financeiras, uma vez que os custos elevados dos tratamentos podem ser inacessíveis para muitos, especialmente em países em desenvolvimento **[11]**. A disponibilidade geográfica de clínicas e especialistas em reprodução assistida também é limitada em regiões menos desenvolvidas, criando disparidades no acesso aos tratamentos **[12]**. Ademais, há uma necessidade premente de maior divulgação e educação sobre as opções de tratamento e seus benefícios, para que os pacientes possam tomar decisões informadas **[13]**.

Um artigo publicado em 2015 informou que os países em desenvolvimento abrangem a maioria dos casos de infertilidade **[11]**, chegando em 30% a taxa em algumas populações **[14]**. A alta prevalência em determinadas regiões pode sugerir

estilo de vida ou problemas ambientais que afetam a fertilidade da população local **[15]** ou disparidades de acesso ao especialista médico. Por consequência, pode-se verificar a ânsia de mulheres e homens pela oportunidade em se tratar e a complexidade de acesso aos serviços médicos e aos diversos tratamentos existentes **[16]**. Em algumas culturas, ainda existe um aumento da carga social sobre a infertilidade que pode levar a sentimento de culpa, solidão e estresse social **[17-18]**.

Observa-se assim, a necessidade em manter uma discussão ética sobre acessibilidade de tratamento para infertilidade, pois estudos mostram um acesso não igualitário aos tratamentos de reprodução assistida ou mesmo à primeira consulta com um especialista em fertilidade por motivos como (i) localização: países ou estados menos desenvolvidos, (ii) financeiro: alto custo do tratamento e saúde pública que não oferece estes tratamentos, (iii) disparidades raciais e étnicas **[14,19]** e, (iv) falta de divulgação ou comunicação: casais permanecem ignorantes ao problema de saúde e à possibilidade de tratamento. Dessa forma, o tratamento de reprodução assistida apresenta-se ausente ou inacessível para muitos casais inférteis pelo mundo e prevê-se uma questão ética muito importante: o esclarecimento dos direitos reprodutivos de forma justa e igualitária **[20]**.

A discrepância de acesso aos tratamentos de infertilidade pode ser notada em diversas regiões do mundo, tornando-se mais evidente em populações mais vulneráveis e instigando a questão se os cuidados reprodutivos não estão sendo praticados mais como um privilégio do que como um direito **[21]**. Assim, percebe-se em primeiro, a carência legislativa para garantir acesso igualitário a todos, em segundo, como os grupos mais vulneráveis ainda dependem da força da justiça e, por fim, a importância de ações médicas em planejar formas de vencer as limitações de acesso experimentadas por algumas pessoas inférteis, exercendo o princípio ético da justiça.

Compreender as questões éticas que envolvem as limitações de acesso ao cuidado reprodutivo e planejamento familiar e recolher dados demográficos e socioeconômicos de pacientes vulneráveis através de um questionário que permite captar os sentimentos e opiniões dos participantes, pode fornecer dados para adaptar políticas e tratamentos de forma mais equânime, bem como para aumentar a discussão ética sobre a desigualdade no acesso aos cuidados. Com isso, a presente tese visou abordar a dificuldade dos casais inférteis no acesso aos tratamentos de infertilidade nos países em desenvolvimento, centrando-se na essência do princípio

da justiça. Para alcançar esse objetivo, foram realizadas quatro abordagens para o estudo, resultando em quatro artigos científicos:

a) **artigo 1** - levantamento bibliográfico sobre o tema para identificar as questões éticas envolvidas e compreender como estão evoluindo as discussões e a conscientização sobre a justiça na prestação de cuidados médicos e oportunidades de tratamento para infertilidade a casais em todo o mundo;

b) **artigo 2** - elaboração de questionário com o propósito de caracterizar a população alvo e identificar as principais barreiras de acesso aos cuidados reprodutivos;

c) **artigo 3** - análise de qualidade de vida de pacientes com infertilidade, investigando se a espiritualidade religiosa colabora como um mecanismo de enfrentamento e,

d) **artigo 4** - com base na literatura e na identificação das principais dificuldades de acesso aos cuidados médicos reprodutivos apontados por uma parcela da população brasileira, apresentação de uma discussão bioética ampla sobre a busca do princípio da justiça para casais inférteis.

Dessa forma, a estrutura da tese foi organizada de maneira a proporcionar uma análise integrada e abrangente do tema, começando com uma fundamentação teórica que contextualiza as questões éticas (*Artigo 1 - Bioethics in the adversities of access to infertility treatment*). A seguir, a pesquisa empírica é apresentada, primeiro com a caracterização da população estudada e identificação das barreiras de acesso (*Artigo 2 - Access to infertility care in Brazil: validation of a questionnaire for a bioethical discussion*), e posteriormente, com a avaliação do impacto da infertilidade na qualidade de vida e o papel da espiritualidade como estratégia de enfrentamento (*Artigo 3 - Quality of life in infertile patients in Brazil: religious spirituality as a coping mechanism*). Finalmente, o último artigo sintetiza as informações coletadas e propõe uma discussão bioética sobre a justiça no acesso aos tratamentos de infertilidade (*Artigo 4 - The search for the principle of justice for infertile couples: characterization of the brazilian population and bioethical discussion*). Esta organização permite uma compreensão clara e coesa da inter-relação entre os diferentes aspectos estudados, oferecendo uma visão holística das dificuldades enfrentadas pelos casais inférteis e propondo caminhos para promover maior equidade no acesso aos cuidados reprodutivos.

2. Enquadramento teórico

2.1 Bioethics in the adversities of access to infertility treatment.

Artigo aceito para publicação na Revista Bioética do Conselho Federal de Medicina.
Drauzio Oppenheimer, Christiane Peres Caldas, Francisca Rego, Rui Nunes

Abstract

Introduction: There are barriers that couples face in benefiting from medical care and specialized treatments to become pregnant, which leads to a mobilization that seeks equal access to assisted human reproduction treatments. It is important to identify the ethical issues involved and understand how discussions about justice occur in the provision of medical care and infertility treatment. Method: A literature review was carried out using the Web of Science, Pubmed and Google Scholar databases. Literature review: It was possible to identify that most countries do not meet the ethical requirements of distributive justice. The articles demonstrate the barriers to access and the resistance that exists to accepting infertility as a health problem. They also demonstrated the suffering that infertility causes and the urgency of putting ethical concepts into practice so that solutions can be adopted. Conclusion: An ethical debate that achieves the provision of well-being for all individuals can improve health and is also related to the feeling of justice on the part of health professionals and policymakers.
Keywords: Access to health. Bioethics. Infertility. Human reproduction. Reproductive rights

Introduction

The World Health Organization (WHO), since 2009, assumes infertility as a disease and a global public health problem (1) that can affect approximately 15% of couples of reproductive age (2), generating an unexpected situation of distress and stress (3). In addition, throughout the world, there are several barriers or impediments that some couples face to benefit from specialized medical care and treatments to achieve pregnancy (4), which leads to discussions and mobilizations that seek distributive justice and equal access to medical centers and assisted human reproduction treatments.

In several countries, there is no specific law on the right to infertility treatment, but it is important to note that the concept of reproductive justice is based on four fundamental principles and one of them is that everyone has the right to have children (5). An article published by the European Society for Human Reproduction and Embryology (ESHRE) in 2008 reinforces that the right to equal access to basic health care is essential to ensure that people have a range of opportunities for medical care, regardless of their income or financial means6. It also informs that the most important factor that causes disparity in access to health care is the individuals' ability to pay (6).

Concomitantly, medical conduct based on ethical principles stands out: respect for autonomy of choice, beneficence, non-maleficence and, especially in the current context, justice (7). The principle of justice provides the patient with fair and equitable access to available health services (8). It is also important to emphasize that ethics and law must accompany advances in the area of reproductive medicine to enable humanist conduct and followers of rights. The look of ethics and biolaw recalls that treatment in the health area should override any lucrative purpose and prioritize the good of life (9).

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

However, even observing millions of cases of successful assisted reproduction treatment and admiring the medical and technological evolution of these treatments, it is also noteworthy the impossibility or difficulty of access experienced by many infertile couples, especially in developing countries or poorer regions (11). In this manner, it appears that despite the existence of recognition, even if still insufficient, for the right to reproductive health and family planning, many couples still witness the lack of opportunity, whether financial, social, communication or location, to carry out treatment for infertility to achieve motherhood and fatherhood.

At the same time, when considering the different circumstances in which a population lives, a study published in 2017 raises an important point that confirms the need to propose tools to make it feasible to reach quality health services considering the resources available from a specific community, and it is essential to assume the difficulty in providing the right to the same state of health for all, as there are different conjunctures, such as family, social and economic conditions (13).

Finally, promoting the universal right of access to health care is still a challenge and we recognize that it is unfeasible to idealize the right to services to treat infertility for all individuals without observing the particularities of a community and without involving a bioethical content, as the fundamental right to procreate is based on solid moral and ethical concepts (14). With this, it becomes important to identify the ethical issues involved and to understand how discussions and awareness about the fairness of providing medical care and treatment opportunities for infertility to couples around the world are evolving.

Methods

This study was carried out from April to June 2023 through bibliographical research on the theme “Bioethics in the adversities of access to assisted human reproduction”, using the Web of Science, Pubmed and Google Scholar databases, chapters of books and websites of Organizations and Societies. The keywords used were taken from the Health Sciences Descriptors (DeCS): Bioethics, Infertility, Health disparity, Health inequity, Health rights and Reproductive Health Services. The inclusion criterion was articles published from the year 1980 in English or Portuguese.

Literature review

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

Studies claim that infertility has been increasing its incidence and that developing countries cover most cases (4), reaching 30% infertility rate in some populations (15). The high prevalence in certain regions may suggest lifestyle, environmental problems that affect fertility of the local population, and/or disparities in access to medical specialists (16).

When a data survey is carried out to understand how individuals in developed and developing countries have access to infertility treatments, it is identified 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, such as the United Kingdom, where medical treatment is publicly funded and available by the National Health Service (NHS) (17), as policymakers consider infertility to be a disease, some discourses disagree with this (18) and arguments that see infertility only as a failure pointed out by social and cultural pressure to have children (19). However, the literature has an abundance of articles attesting that infertility, for many women and men, is not just about the impossibility of having children, but it is a rupture of life project and continuity, causing psychological suffering and a feeling of inability to achieve primary life expectancy (20-22).

The Universal Declaration on Bioethics and Human Rights (2005) proclaims as one of its objectives (23) (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”. Furthermore, Article 16:1 of the Universal Declaration of Human Rights states that “Men and women of legal age, without any limitation due to race, ethnicity, nationality or religion, have the right to marry and to found a family” and Article 25 includes the right to medical assistance (24). Thus, infertility treatment is considered a human rights issue, but often, in practice, its inclusion as mandatory coverage still depends on justifications (25). Additionally, studies show unequal access to assisted reproduction treatments or even to the first consultation with a fertility specialist for reasons such as (i) location: less developed countries or states, (ii) financial: public health that does not offer more expensive treatments, (iii) racial and ethnic disparities (15,26) and, (iv) lack of disclosure or communication: couples remain ignorant of the health problem and the possibility of treatment. Thus, assisted reproduction treatment is absent or inaccessible for many infertile couples around the world.

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

Evidently, due to advances in the area of reproductive medicine that make possible the chances for a couple or an individual to have children, many lines of thought do not cover all the causes of infertility as a disease. Maung (2019) demonstrates that this argument is important for a medical, ethical, and philosophical debate, as it indicates that the problem with infertility is that it is a heterogeneous category and that there is disagreement about which types of infertility qualify as a disease (18).

In contrast to resistance, a study by Rutstein and Iqbal (2004) demonstrated how most cases of infertility stem from the inability to conceive a healthy baby when analyzing information from 47 demographic and health surveys in developing countries and estimated that, in 2002, more than 186 million married women of reproductive age had primary or secondary infertility (28). Moreover, in addition to the importance of general well-being for the health of a human being, and well-being can even be associated with the realization of motherhood and/or fatherhood, there are numerous causes that can lead couples to need assisted reproduction treatment; for example, in addition to infertility itself, there are people who resort to assisted reproduction techniques to avoid the birth of a child with a specific genetic disease (6).

There is an effort by organizations and medical professionals 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 stands out, which, based on the definition of reproductive justice, seeks to overcome adversities and bring low-cost fertilization treatments to regions with limited resources (4). Even so, it is suggested that public policies should assume infertility as a public health problem and seek financial resources within budgetary allocations or public-private partnerships to alleviate the lack of accessibility. Furthermore, Nunes et al., 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).

Even so, it is perceived that the discussion of offering public funding to treat infertility follows a conservative line and, although it can be rationally understood, the resistant pretexts in providing specialized medical care and treatment financed by the State or covered by medical agreements and health insurance, when we follow ethical principles, 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 (2015), a fundamental step to make a health system with equal access viable implies assuming that it is best to adopt the cost-effectiveness criterion (29) and according to Brown et al. (2016), the strategy of offering public infertility treatment is clear in that it involves an ethical discussion considering 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 problems and cultural (30).

Thus, it is seen that an important point to offer access to all who need treatment is to accept that infertility is a disease because it also causes changes in well-being. However, the ethical discussion still needs to be expanded, because in addition to admitting that infertility is a disease, deeply understanding what the access barriers are, allows knowing the details and drives the search for alternatives and solutions to provide basic healthcare to all. The ESHRE indicates that even in countries that offer reimbursement for infertility treatment through the public system or with insurance coverage, groups with low income and low education make significantly less use of health services, clarifying the importance of educating the population and having an awareness of fertility care and treatment. In addition, ensuring equitable access to infertility assessment, treatment, and care is seen to depend on the investment of health professionals and policy makers (27).

The most current data inform that, for example, black women, when compared to white women, have fewer opportunities to be evaluated and treated for infertility, as well as that the population of lower socioeconomic status seeks less infertility services (31). Ombelet et al. (2008) points out that even with the implementation of low-cost treatments, it is unlikely to become accessible to everyone, and that for men and women living in extreme poverty, the ideal would be socio-political interventions in favor of improving the economic situation (32). Despite identifying possible barriers to access, we still face great difficulty in interpreting the causes in a way that brings efficient solutions. Corroborating this thought, Perritt and Eugene (2021) state that access inequalities are poorly understood and suggest racism and economic contrast as likely causes (27).

Bahamondes and Makuch (2014) referred to 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, the current study analyzed through a survey of the literature that infertility affects individuals with

different conditions around the world, but much emphasis is placed on the fact that the preventable causes of infertility are different between some groups, and therefore, perhaps different actions are necessary. For example, it is indicated 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). It follows that preventive public health policies and better assistance to this group would already have a positive effect on the reduction of the incidence of infertility. However, the avoidable cause of infertility and the search for treatment by economically stable people can be justified due to the postponement of motherhood, prioritizing career achievement, or financial stability. In many Western countries, women try to conceive their first child after achieving other goals in life, when fertility possibly begins to decline (35). Additionally, cultural, and environmental factors interfere with fertility and differ between regions and countries (36).

With this, it can be considered that the ethical debate should have the same primary objective in designing distributive justice, but could have different approaches, according to different scenarios, to then achieve equity of access. In favor of this premise, White et al. (2006) expose the issue of sociocultural barriers, indicating language obstacles, communication elements, notions of privacy and prejudices about health care (37). In any case, the magnitude of the suffering that infertility causes in people's lives is observed and, therefore, the urgency of this awareness and of putting ethical concepts into practice so that solutions are adopted by health professionals and politicians. As exposed by Nunes et al., it is important to strive for a healthy society, thus being more balanced and productive. To achieve this, there must be efforts on a global scale to implement human rights in an accelerated manner and the right of access to health must be considered a priority, even if it still depends on citizen solidarity to be enjoyed (13).

Conclusion

Arguably, with the review of the literature, it is noted that overcoming the barriers to accessing infertility treatments depends on a comprehensive and continuous ethical approach. In addition to the most exposed difficulties in access, such as financial issues, social issues, racial issues, and location, there are still differences in considering infertility a disease, the costs of treatment financed by the State, and the discussion on offering infertility treatment to couples in extreme poverty.

With the analysis herein, it could also be observed that autonomy and justice are the ethical principles most involved in this discussion. This has led, in addition, to enunciate an ethical debate with various points depending on the quality of life conditions, expectations and consequences on people's lives in different parts of the world. It becomes clear that globally, that is, not only in developing countries, but also in developed countries, there is a need to adopt measures for the fulfillment of human rights, prioritizing health care depending on the context of each nation or country location.

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

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3. Objetivos

A presente tese teve como objetivo aprofundar e atualizar o conhecimento e a discussão sobre a dificuldade de acesso aos tratamentos de infertilidade nos países em desenvolvimento, com foco no princípio da justiça.

Foram determinados os seguintes objetivos específicos:

- Identificar as características socioeconômicas dos casais com infertilidade atendidos nos estados de São Paulo e Minas Gerais - Brasil;
- Identificar como as barreiras aos cuidados de infertilidade afetam as populações mais vulneráveis;
- Analisar o impacto da infertilidade na qualidade de vida das mulheres, tendo a religiosidade como mecanismo de enfrentamento.

4. Método

Estudo observacional transversal, multicêntrico, realizado por aplicação de questionário *on-line* (Google Forms) com base em um levantamento bibliográfico, desenvolvido para efeito deste estudo, a casais que procuraram atendimento médico para engravidar em duas clínicas de reprodução dos estados de São Paulo (SP) e Minas Gerais (MG), entre setembro de 2021 e janeiro de 2022. Este estudo foi aprovado pelo Comitê de Ética em Pesquisa (CEP) da Faculdade de Medicina de Itajubá (CAAE: 50434521.6.0000.5559). O estudo foi composto por 211 casais, que responderam adequadamente ao questionário. Todos os participantes incluídos assinaram um termo de consentimento livre e esclarecido concordando em participar do estudo, e as diretrizes do Conselho Nacional de Ética em Pesquisa foram seguidas.

O questionário foi aplicado a casais maiores de 18 anos e foram excluídos os participantes que não preencheram corretamente o questionário. Como o estudo se concentrou no acesso aos cuidados para casais que tentavam ativamente engravidar sem assistência médica anteriormente, os casais homossexuais e as mulheres solteiras também foram excluídos desta análise.

4.1 Levantamento de dados

O levantamento bibliográfico foi realizado nas bases de dados PubMed, Google Scholar, LILACS, Web of Science e SciELO e em sites da internet para informações jurídicas. Para a pesquisa foram utilizadas as palavras-chave: infertilidade, bioética, ética baseada em princípios, justiça e tratamento de reprodução assistida e, os artigos selecionados foram os publicados em inglês desde 1998 até a presente data.

4.2 Elaboração e validação do questionário

As duas etapas seguintes à revisão da literatura foram a elaboração do questionário e a validação do estudo piloto **[22]**, conforme descrito a seguir.

Elaboração do questionário

A produção dos itens do questionário foi realizada por pesquisadores da área de reprodução humana e bioética. Foram elaboradas trinta questões, sendo 24 nominais (sim/não) e 06 abertas, com o objetivo de absorver conhecimentos sobre

identidade pessoal, cultural, econômica e social, além de identificar as principais dificuldades dos participantes no acesso aos cuidados reprodutivos. As questões foram organizadas de acordo com os assuntos: (a) características sociodemográficas do casal, buscando saber a idade, cor/raça e escolaridade dos participantes; (b) tempo de infertilidade, tentativas de engravidar e causa da infertilidade; (c) impacto da infertilidade na vida do casal, ou seja, se o relacionamento do casal foi fortalecido ou fragilizado devido à infertilidade e se estão passando ou passaram por momentos de ansiedade e estresse, além de apontar a percepção de qualidade da vida; (d) experiências de busca de atendimento e tratamento para infertilidade, identificando a cidade onde os casais realizaram ou farão o tratamento e as dificuldades de acesso ao tratamento necessário e, por fim, (e) condições sociais e econômicas.

O questionário foi validado através da elaboração de artigo científico já publicado: *Access to infertility care in Brazil: validation of a questionnaire for a bioethical discussion* - Oppenheimer D, Caldas CP, Rego F, Nunes R. *Reprod Health. 2023 Dec 8;20(1):183. doi: 10.1186/s12978-023-01724-7.*

Pré-teste

Para o pré-teste, o questionário *on-line* foi aplicado a 15 casais maiores de 18 anos que procuraram tratamento médico para infertilidade conjugal e aceitaram participar do estudo. Foi possível observar se os participantes tiveram dificuldade ou não em responder ao questionário e, após análise estatística, se as informações obtidas foram satisfatórias.

4.3 Aplicação do questionário

Após validação no estudo piloto, o questionário foi aplicado a 211 casais atendidos na Clínica Oppenheimer e na Clínica de Fertilidade e Reprodução Humana Gera entre setembro e dezembro de 2021.

4.4 Análise estatística

Para análise estatística foi utilizado o software SPSS 18.0 para Windows. Inicialmente foi realizada uma análise descritiva dos dados. Para as variáveis numéricas contínuas foram apresentados média, desvio padrão e intervalo de confiança de 95% (IC95%) das médias. Para variáveis numéricas discretas foram

apresentados mediana, intervalo interquartil, mínimo e máximo. Para frequências foi calculado o percentual e seu IC95%. A correlação entre as variáveis foi verificada por meio do teste de correlação de Pearson (entre duas variáveis numéricas contínuas) ou teste de correlação de Spearman (todos os outros casos). Foi adotado um alfa de 5%.

5. Resultados

Os resultados estão apresentados através dos artigos formulados:

5.1 Validação do questionário para caracterização da população brasileira infértil e as barreiras ao acesso à saúde reprodutiva.

Access to infertility care in Brazil: validation of a questionnaire for a bioethical discussion

Oppenheimer D, Caldas CP, Rego F, Nunes R.

Reprod Health. 2023 Dec 8;20(1):183. doi: 10.1186/s12978-023-01724-7.

Abstract

Background: The World Health Organization characterizes infertility as a disease since 2009; however, in many countries, reproductive health is not prioritized. Characterizing a target population and knowing the barriers to accessing reproductive care may allow for a broadening of the discussion on how to provide equal opportunities. The objective of this study was to develop and validate a questionnaire that seeks to identify socioeconomic and cultural characteristics of Brazilian infertile couples to open the discussion on the principle of fair access to health. Methods: (1) literature review in the main databases, (2) questionnaire elaboration by researchers within the areas of human reproduction and bioethics, concerned with content adequacy and comprehension, using the Google Forms online platform, (3) pilot study - the questionnaire was applied to 54 couples, over 18 years of age, that were seeking infertility treatment and accepted to participate in the study and (4) statistical analysis - for continuous numerical variables, mean, standard deviation and 95% CI of the means were presented. For discrete numerical variables, median, interquartile range, minimum and maximum were presented. Results: Forty-four questionnaires were fully completed and with adequate answers. The questionnaire proved to be objective and easy to understand. It was possible to obtain information on education, race of the couple, the impact of infertility on the couple's life, socioeconomic conditions, and the main difficulties in accessing medical care for treatment of infertility. Conclusion: The questionnaire proved to be feasible in collecting appropriate information to characterize

a target population and the only limitation was that there was no academic expert evaluation before the pilot test.
Keywords: Infertility, medical infertility access, questionnaire validation.

Background

The principles set forth in 1995 by the World Health Organization (WHO) in regard to reproductive health state that women have a right to physical, mental, and social welfare [1]. It is therefore imperative to provide appropriate access to reproductive care and support patients that seek to restore fertility and raise their own family [2,3]. However, it has also been recognized that there are geographic, social, economic, political, and biological barriers that impede access to care to a large portion of men and women [4]. This leads to the need to provide better opportunities and access to reproductive medicine for patients who seek low- or high-complexity fertility treatment [5].

Many meetings – such as the 2015 American Society for Reproductive Medicine (ASRM) annual meeting, with participants from throughout the globe – have been organized to propose a strategic plan that aims at providing access to care to all infertility patients. A central point towards achieving this goal and to increase populational access to specialized care and treatments in reproductive medicine is to adequately characterize the population that faces these barriers and to understand the reasons that limit access to reproductive care [5].

Although the WHO classifies infertility as a disease since 2009 [6,7], many specialists note that infertility – and reproductive health – is still not prioritized [8], leading to a lack of assistance or to excessive requirements to include treatments in public or private health systems [9]. Moreover, the cost of treatment, age discrimination, ethnic and racial diversity, social and economic inequality, and religious and cultural beliefs further worsen conditions for these patients. Physical access is also of concern because there is a geographic concentration of practitioners and specialized assisted reproduction clinics, which further hinders patients from accessing care for infertility [5].

Although there is mobilization by medical and scientific societies and patient advocacy groups that have demonstrated disparities in access to medical treatment for infertility [5,10], it is noteworthy that current opportunities in achieving medical assistance for maternity or paternity are largely excluding [11]. Taken together, this

information demonstrates that there aren't trustworthy data regarding the current number of infertile men and women in the Brazilian population and that these data may be skewed in the vulnerable population. Understanding this, and gathering demographic and socioeconomic data from vulnerable patients by means of a questionnaire, which allows the capture of participant feelings and opinions, may provide data so as to tailor policies and treatments in a more equanimous manner, as well as to increase ethical discussion regarding inequality in access to care.

Thus, in order to understand current limitations in access to care for a portion of the Brazilian population and to study possibilities in exercising their right to reproductive health and family planning, the objective of this study was to elaborate and validate a questionnaire that seeks to identify socioeconomic characteristics of infertile Brazilian couples and to identify how current barriers to infertility care affect vulnerable populations.

Materials and Methods

An observational study to develop a questionnaire and determine difficulties in access to reproductive care for infertile couples in the states of Minas Gerais and São Paulo – Brazil was carried out. An ongoing validation study is underway to broaden and update knowledge on difficulty in access to care in developing countries. A pilot study was thus conducted to validate this questionnaire. Institutional review board approval was obtained from the Itajubá School of Medicine (project number 4.920.415). Only couples seeking to achieve paternity/maternity were included.

In order to develop and validate the questionnaire, four steps were carried out: (i) literature review, (ii) questionnaire elaboration, (iii) pilot study, (iv) statistical analysis.

Literature review was carried out using the Pubmed, SciELO, LILACS, and Web of Science databases, to generate content for questionnaire elaboration. Search terms used were: access to care, assisted reproduction, biomedical ethics, fertility care, infertility, and infertility questionnaire. No constraints were set for publication date or language.

The questionnaire was elaborated using Google Forms by researchers within the areas of human reproduction and bioethics, concerned with content adequacy, objectivity, clarity, ease of reading, and comprehension. Twenty-three questions were elaborated, eighteen in a nominal response scale and five open questions that aimed

at identifying personal, cultural, socioeconomic identities, and the main difficulties in access to reproductive care. Questions were separated in: couple characteristics, duration of infertility, impact of infertility on couple's life, personal experiences when seeking reproductive care and treatment, and socio-economic characteristics.

The questionnaire was applied to fifty-four couples, over 18 years of age, seeking medical treatment for conjugal infertility who consented to participate in the study. Data were collected by via Google Forms questionnaire.

It was possible to observe whether the participants found it difficult or not to answer the questionnaire and, after statistical analysis, whether the information obtained was satisfactory.

Statistical analysis was carried out using SPSS 21.0 for Windows®. Initially, a descriptive analysis of the data was performed. For continuous numerical variables, mean, standard deviation and 95% confidence interval (95% CI) of the means were presented. For discrete numerical variables, median, interquartile range, minimum and maximum were presented. For frequencies, the percentage and its 95% CI were calculated. Correlation between variables was verified using Pearson's correlation test (between two continuous numerical variables) or Spearman's correlation test (all other cases). An alpha error of 5 % adopted for the study.

Results

Fifty-four questionnaires were administered over a period of two months. Ten questionnaires were incomplete or with unsatisfactory answers and 44 questionnaires were fully completed and with adequate answers to the questions. Only 3 items led to no response or inconsistent answers, which were about treatment location, duration of infertility, and number of previous treatments (table 1).

Table 1. Observed inconsistencies in the questionnaire.

Which city will the couple perform the treatment?	***How long is the couple's infertility?***	***What were the number of attempts (treatment) to get pregnant?***
14 years	homosexual couple	NO ANSWER
we haven't chosen yet	I don't have eggs	infinite
	Vasectomy	several
	undetermined	I don't know the exact number

Age and duration of infertility data are presented in table 2. Analysis of the partners showed that the lowest age for the wives was 24 years old and the highest age was 48 years old. In relation to the husbands, the youngest was 24 years old and the oldest was 53 years old. The time of infertility varied between 1 year and 20 years, as shown in the table below. Most wives were older than 35 years and husband age was normally distributed ($p>0.05$ in a Kolmogorov Smirnov test). Most patients reported less than 10 years of duration of infertility.

Table 2. Age of the partners and duration of infertility.

Variable	Value
Wife age (years)	
Mean (Standard Deviation)	36.5 (5.552)
95% CI	34.98; 38.02
Min – Max	24 – 48
Husband age (years)	
Mean (Standard Deviation)	38.83 (7.368)
95% CI	36.85; 40.84
Min – Max	24 – 53
Duration of infertility (years)	
Mean (Standard Deviation)	6.290 (4.102)
95% IC	5.124; 7.456
Min – Max	1 - 20

Demographic data are presented in table 3. In total, 33% of wives and 29.6% of husbands had completed higher education, and all wives reported at least having completed high school education. Most wives (68.5%) and husbands (72.2%) were self-declared white. Regarding the number of previous treatments, three couples indicated numerous attempts and, therefore, were unable to inform the exact amount. Only 2 couples indicated more than 5 attempts and most of the participating couples (56%) indicated 1 or 2 attempts. A total of 13% of couples had previous paternity/maternity. Moreover, 50% of couples presented with a female cause of infertility, 14.8% a male cause, 18.5% a mixed cause, and 9 couples presented with unexplained infertility (table 4).

Table 3. Demographic data.

Variable	Wife	Husband
Education		
Elementary school	0	4 (7.4%)
High school	15 (27.8%)	19 (35.2%)
College degree	18 (33.3%)	16 (29.6%)
Incomplete college education	4 (7.4%)	5 (9.3%)
Post-graduation	17 (31.5%)	10 (18.5%)
None of the alternatives	0	0
Color or race		
Asian	0	2 (3.7%)
White	37 (68.5%)	39 (72.2%)
Indigenous	0	0
Brown	16 (29.6%)	11 (20.4%)
Black	1 (1.9%)	2 (3.7%)

Table 4. Number of previous treatments, infertility cause and previous paternity/maternity.

Question. Will the couple undergo infertility treatment in another city?	
NO	50%
YES	50%
Question. What was the number of attempts (treatment) to get pregnant?	
Answer: 0	18%
Answer: 1	32%
Answer: 2	24%
Answer: 3	14%
Answer: 4	6%
Answer: 5	2%
Answer: 9	2%
Answer: 12	2%
Question. What is the cause of infertility?	
FEMALE	50%
MALE	14.8%
MIXED FACTOR	18.5%
INFERTILITY WITHOUT APPARENT CAUSE	16.7%
Question. Does the couple already have children?	
NO	87%
YES	13%

When asked about how infertility has impacted the couple's life, 38.9% stated that infertility strengthened the couple's relationship, 18.5% stated that the relationship had weakened and 42.6% believed that infertility did not impact the relationship either positively nor negatively. Regarding anxiety or stress due to infertility and the search for treatment, most couples (51.9%) admitted moments of anxiety from the beginning and 31.5% said they developed anxiety only after treatment attempts. Despite this, 72.2% of couples consider they have a good quality of life.

Half of the couples (50%) sought treatment in a different city from which they reside. In accordance, 42.6% of the participants reported that access to specialist and medical services was easy only after indication or assistance, and 22.2% considered it difficult to access. Additionally, even though most participants (40.7%) rated access to an assisted reproduction clinic and treatment options as easy, 59.3% experienced difficulty or ease only after searching in another city. Even so, more than half of the couples (55.6%) did not think about giving up on treatment due to access difficulties (table 5).

Table 5. Impact of infertility and difficulty accessing treatment.

Question. How does infertility impact/impact the couple's life?	
STRENGTHENED THE RELATIONSHIP	38.9%
WEAKENED THE RELATIONSHIP	18.5%
NO POSITIVELY OR NEGATIVELY IMPACT	42.6%
Question. Did infertility and the search for treatment cause moments of anxiety/stress in the couple's life?	
NO	16.7%
YES, ONLY AFTER SOME TREATMENT ATTEMPTS	31.5%
YES	51.9%
Question. The couple considers their quality of life:	
GOOD	72.2%
EXCELLENT	22.2%
BAD	5.6%
Question. Access to specialist and medical services to treat infertility was:	
DIFFICULT	22.2%
EASY	35.2%
EASY, ONLY AFTER INDICATION/HELP	42.6%
Question. Access to the assisted reproduction clinic and infertility treatment options was:	
DIFFICULT	20.4%
EASY	40.7%
EASY, AFTER SEARCHING IN ANOTHER CITY/STATE	38.9%
Question. Has the couple ever thought about giving up on infertility treatment due to some access difficulty?	
NO	55.6%
YES	44.4%

Regarding the perception of medical care, most couples (68.5%) felt welcomed when seeking medical services and treatments, and the rest of the couples were able to express whether they felt helpless or were welcomed after frustrations. Interestingly, only 26% of the couples did not seek more than one medical service, 37% sought care where they were best received and 37% sought care that was financially adequate. An important point about the search for financially adequate treatment is that 83.3% of couples were unaware of free treatment opportunities in other countries.

Furthermore, among the 5 difficulties in accessing medical services and/or treatments, financial issues (high cost of treatments) were the most selected alternative (57.4%). Location (11.1%) and discrimination (1.9%) were also recorded. Exemplifying the financial difficulty, 74.1% of couples recognized an impact on the family budget due to the cost of treatment and 55.6% needed a period between the indication of treatment and the completion of the procedure to raise financial resources. Most (61.1%) of participants did not need to resort to loans or dispose of assets to pay for treatment and 63% did not seek coverage by a health plan or the public health system for assisted reproduction treatment (table 6).

Table 6. Difficulties in accessing medical services and/or treatments.

Question. Did the couple feel welcomed in seeking medical services and/or treatment for infertility?	
NO	9.3%
YES	68.5%
YES, AFTER SOME FRUSTRATIONS	22.2%
Question. Did the couple seek more than one medical service to treat infertility?	
NO, AS IT DOES NOT KNOW OTHER POSSIBILITIES	13%
NO, BECAUSE THERE ARE NOT MANY OPTIONS IN YOUR LOCATION	13%
YES, SEARCH FOR ADEQUATE SERVICE FINANCIALLY	37%
YES, SEARCH FOR THE BEST WELCOME SERVICE	37%
Question. Has the couple sought or is aware of free treatment in other countries?	
NO, NO KNOWLEDGE	83.3%
YES. HAS KNOWLEDGE, BUT HAS NOT OBTAINED ACCESS TO THE OTHER COUNTRY	1.9%
YES. HAS KNOWLEDGE, BUT HAS NOT TRIED TREATMENT	14.8%
Question. Point out the greatest difficulty encountered by the couple to access medical services and/or treatment for infertility:	
DISCRIMINATION	1.9%
FINANCIAL	57.4%
LOCATION	11.1%
LOCATION + FINANCIAL	14.8%
DIDN'T FIND DIFFICULTY ACCESS	9.3%
OTHER	5.6%
Question. Has the cost of treatment impacted the family budget?	
NO	25.9%
YES	74.1%
Question. Was there a need to take out loans, have assets or a similar situation to pay for infertility treatment?	
NO	61.1%
YES	38.9%
Question. Was there a need to wait between the diagnosis, the indication of treatment and the performance of the procedure to obtain financial resources?	
NO	44.4%
YES	55.6%
Question. Did the couple seek coverage from health care providers ir the public health system for treatment of infertility?	
NO	63%
YES, BUT THEY DID NOT FIND ANY	37%

When asked about their socioeconomic status and family income, the vast majority of couples indicated tranquility, where 81.5% said they had a good socioeconomic situation, 3.7% declared an excellent situation and 14.8% thought their socioeconomic situation was bad. A family income between R$ 3,000 and 5,000 was observed in 53.7% of responders, 31.5% of the couples indicated that they had a family

income between R$ 5,000 and R$ 10,000, 7.4% did not fit into the income ranges presented by the questionnaire, 3.7% answered that they had income between R$ 10,000 and R$ 15,000, and 3.7% between R$ 15,000 and R$ 20,000. No participating couple reported having a family income equal to or above R$ 25,000 (table 7).

Table 7. Socioeconomic status and family income.

Question. The couple considers their socioeconomic status:	
GOOD	81.5%
EXCELLENT	3.7%
BAD	14.8%
Question. What is the gross family income?	
R$ 3.000 A R$ 5.000	53.7%
R$ 5.000 A R$ 10.000	31.5%
R$ 10.000 A R$ 15.000	3.7%
R$ 15.000 A R$ 20.000	3.7%
R$ 25.000 OR MORE	0%
NONE OF THE ALTERNATIVES	7.4%

Additionally, to know the range of the population that seeks treatment for infertility, the questionnaire showed that three out of four couples (75.9%) know friends or have acquaintances who have sought treatment, and several participating couples (37.5%) pointed out that these friends were not able to access infertility treatments.

Correlation analysis showed that 95.7% of patients who sought assistance at another city than where they live had already attempted at least one treatment cycle, while only 68% of patients who sought treatment where they lived had already attempted at least one treatment cycle (p=0.024).

It is important to note that, in accordance with results presented above, 61.5% of couples who sought treatment in another city/state found it easy to access the assisted reproduction clinic and treatment options only after seeking treatment in a different city from which they reside. Also, 57.7% of couples that did not seek treatment in another city, considered they had easy access (p=0.003).

The questionnaire also reported that 42.3% of couples who did not seek treatment in another city sought more than one medical service to treat infertility. Furthermore, 46.2% of couples who sought treatment in another city were looking for

a more receptive environment (p=0.032). 73.1% of couples who responded they had not sought treatment in another city and 92.3% who had reported they were not aware of free treatment in other countries. However, expectedly, 26.9% of couples who did not find treatment in another location admitted to having knowledge about the gratuitousness in other countries (p=0.048).

Finally, it was possible, by this questionnaire, to obtain information about the main difficulties in accessing medical care to treat infertility, where 80.8% of couples who did not seek treatment in another city pointed out that the high cost is the greatest adversity for carrying out the treatment. In accordance, 30.8% of respondents who selected to have sought treatment in another city also found the financial issue as the main limiting factor. Furthermore, it was shown that 23.1% of the couples in the same group indicated the location, that is, living in a city with few resources, as the greatest difficulty encountered by the couple to achieve treatment (p=0.003).

Discussion

Infertility is a worldwide public health problem [9], but access to care is heterogeneous, which makes it necessary to observe populations in a more individualized way in order to obtain perspective on the impacts of infertility in men and women under diverse locations, financial, and social realities. An instrument was thus developed and validated to address these aspects within a population of infertile couples. It is important to note that the development of the questionnaire took into account validation of the research instrument so that there is methodological coherence and consistency of results [12,13].

The questionnaire developed sought to identify the socioeconomic positions of several patients with infertility who sought medical assistance in São Paulo and Minas Gerais (Brazil), and to identify difficulties in access to reproductive care experienced by the target population, in order to better understand the limits of access to reproductive care and, with that, plan and develop mechanisms to exercise the right to reproductive health and family planning. In this validation study, we observed that the questionnaire was simple to administer, and feedback from patients showed that it was easy to understand, with no need for adjustments. In addition, results demonstrated internal consistency, so that the questionnaire is a valid instrument and allows obtaining information that is statistically possible to be analyzed.

Results analysis allowed us to characterize the main characteristics of participants, indicating age, duration of infertility, level of education, and color or race. Furthermore, it made it possible to understand the patients' anxiety with the open answers regarding the number of treatment attempts, where some couples indicated that they no longer keep track of the count, and referring to the biggest difficulty encountered by the couple to access medical services and/or treatment, where couples were able to express their particular difficulty. Additionally, the last two items of the questionnaire showed how there is a still unknown infertile population.

Corroborating with several authors [5] and as an important factor in discussions aimed at reproductive health rights, the main barriers to reaching treatment were cost of treatment, followed by concentration of clinics in larger cities. Financial sensibility was also an important deciding factor, and a driving force in leading couples to seek treatment alternatives. In addition, the questionnaire exposed how couples assess their quality of life, focusing on the socioeconomic status and possible stress and anxiety in the couple's life. Finally, correlation analysis brought data that support the information acquired, managing to exemplify the main difficulties in accessing treatments to treat infertility and the search for its scope.

In conclusion, the questionnaire proved to be feasible in collecting appropriate information to characterize a target population; that is, the questionnaire was able to meet the main purpose of the study, and the only limitation found was that there was no evaluation by academic judges prior to the pilot test. Even so, the questionnaire proved to be easy for couples in the survey to understand.

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5.2 Qualidade de vida e a religiosidade em pacientes inferteis

Title: Quality of life in infertile patients in Brazil: religious spirituality as a coping mechanism.

Artigo aceito para publicação na Revista Acta Bioethica.

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Abstract

Background: Due to social pressure and individual desire to have children, infertility is often accompanied by suffering and decreased quality of life. Among possible coping mechanisms, religion has been suggested to help improve quality of life. The objective of this study was to verify, in a cohort of Brazilian women undergoing infertility treatment, if there is a relationship between religiosity and quality of life. Methods: The sample consisted of 104 volunteer Brazilian women who sought infertility treatment. A FertiQoL and a Religiosity questionnaire were administered. Descriptive statistics were computed, and groups were compared using a Chi-square test. Results: Most of the participants in the study stated that religiosity is associated with well-being, and 90% of them concluded that religiosity was an important process during infertility treatment. The study found that religiosity leads to improved adaptive coping capacity. Conclusions: Although it is difficult to demonstrate causality, results strongly suggest that religiosity plays an important role in adjusting the psychological aspects of infertile women.

Keywords: Female infertility; fertilization clinics; medicine; quality of life; religion.

Background

Infertility, defined as the failure to conceive after one year of regular sexual intercourse without the use of contraceptive measures [1], is considered a global health issue [2]. It is estimated that 15% of couples are infertile, and a 50% increase in cases has been observed over the past two decades [3].

The desire to bear children and constitute a family is a constituent of human instinct and, under this premise, infertility has a potentially devastating effect on couples, leading to negative emotional effects and impacting various aspects of

conjugal life [4]. In some cultures, there is still an increased social burden of infertility that may lead to feelings of guilt, loneliness, and social stress [5,6].

Some authors have observed a relationship between infertility and conjugal dissatisfaction or distress, with negative effects on conjugal life [7]. Moreover, although a male factor is as prevalent as a female factor [8], many still consider infertility mostly a female issue, especially in developing countries, or in countries where a maternal role is valued over the women themselves [7,9].

Moreover, the impact of infertility leads many couples to physical, psychological, social, and spiritual distress, leading to questions regarding their existence [10,11]. In order to achieve emotional balance, some couples embark on a spiritual journey, seeking new meaning or purpose in life through understanding negative events [11,12]. A Koenig review (2012) pointed an association between spirituality/religiosity with quality of life and mental health, demonstrating a positive association with emotions such as hope, optimism, and purpose or meaning [13].

Although there is no consensus on the definitions of religiosity and spirituality, Renetzky (1979) designates the spiritual dimension as: (i) the power within the human being, giving meaning, purpose, and fulfillment to life, suffering and death; (ii) the individual's will to live; and (iii) the individual's belief and faith in himself, others, and God. In this way, religious practices and spiritual beliefs are involved by similar feelings [14] and, the context of this study, sought to analyze how much spirituality in connection with religion and the strengthening of the bond with faith reflects on the quality of life of the participants.

Studies have shown that belief in a divine being or eternal life may lead to increased resilience; likewise, infertile couples have been shown to seek counseling from religious leaders more often than from psychologists or support groups [12,15]. It is also noteworthy that patients who have incorporated prayers into their infertility treatment routines have obtained increased success rates, and that religion is a good coping strategy for patients with traumatic and adverse situations [16,17].

Diagnosis of infertility is often difficult, both physically and mentally, and different coping mechanisms are often experienced throughout treatment. In this study, we set out to assess, in a cohort of Brazilian women undergoing infertility workup and treatment for conjugal infertility, if religion is related to quality of life.

Methods

A cross-sectional study was carried out at the Assisted Reproduction Clinic – Gera Clinic – São Paulo unit. A total of 104 women were included, aged between 18 and 50 years old. Inclusion criteria were age (between 18 and 50 years old) and a diagnosis of conjugal infertility. Institutional review board approval was received from the Itajubá School of Medicine (project number 3.846.249). Resolution 196/96 guidelines from the Brazilian National Health Council were followed.

Data were collected by via a Google Forms questionnaire, sent by email, and included an informed consent where the patient agreed to participate in the study. For data collection, the following questionnaires were applied:

- FertiQoL (Fertility Quality of Life): An instrument translated and revised into Portuguese, consisting of twenty-six items, developed, and validated by Boivin et al. (2011) [18] that allows evaluation of quality of life of men and women who experience fertility problems. Administration time was approximately 10 to 15 minutes.
- General Questionnaire: Questionnaire developed for this current study by Oppenheimer et al. that consists of twelve items that assess religious aspects and the influence of religiousness on the quality of life of women with fertility problems. The questionnaire administration time was approximately 5 minutes. Patients were asked what religion or belief system they adhered to, how often they participated in religious celebrations, and if this helped in coping with infertility, as well as other questions.

Data were analyzed using SPSS 18.0 for Windows®. Descriptive analysis was performed, with the presentation of frequencies and percentages in each group, for the studied variables. Groups were compared using a Chi-square test. Statistical significance was set at 5%.

Results

In total, 104 volunteer women responded to the questionnaires. The first 26 questions corresponded to the FertiQoL questionnaire and the last 12 questions corresponded to the general questionnaire. Results are presented below, according to the order of the questions.

Individual perception of quality-of-life questions demonstrated that 89% of patients undergoing infertility treatment view their health as good or very good, and 61% are satisfied with their quality of life. On the other hand, many patients (67%) reported decreased concentration due to thoughts about infertility.

In terms of dealing with the problems of infertility, 43% of patients reported they were able to advance their life plans despite fertility problems, but 26% find it moderately difficult and 31% reported difficulty. Also, 37% of patients felt very or completely exhausted. However, 53% of respondents felt they were partially able to deal with their problems of infertility.

Several women (45%) were very satisfied with the support they have received from friends, but 35% admitted they were more or less satisfied and 20% said they were little or not at all satisfied with the support they received from friends. Most (69%) also reported they are satisfied with their sex life, despite infertility.

When asked about their feelings, 61% of women reported they never or rarely are jealous or rancorous due to infertility, but most patients report to be anguished: 46% all the time or often, and 35% sometimes. Most (79%) fluctuate between hope and despair rising from infertility, and over half (51%) feel isolated.

Despite the difficulty in achieving pregnancy, 63% of patients report they are affectionate with their partners (and vice-versa), and only 7% report they are rarely or never affectionate.

Half of respondents described their infertility issues interfered with their daily obligations. Moreover, 58% of patients declared discomfort in social situations. However, only 20% felt their family never or rarely understood the problems they were facing, 34% responded their family sometimes understands them, and 46% feel that family members are often or always able to understand the infertility problems they face. Moreover, 53% of women interviewed stated their dedication to their partner was strengthened due to their infertility

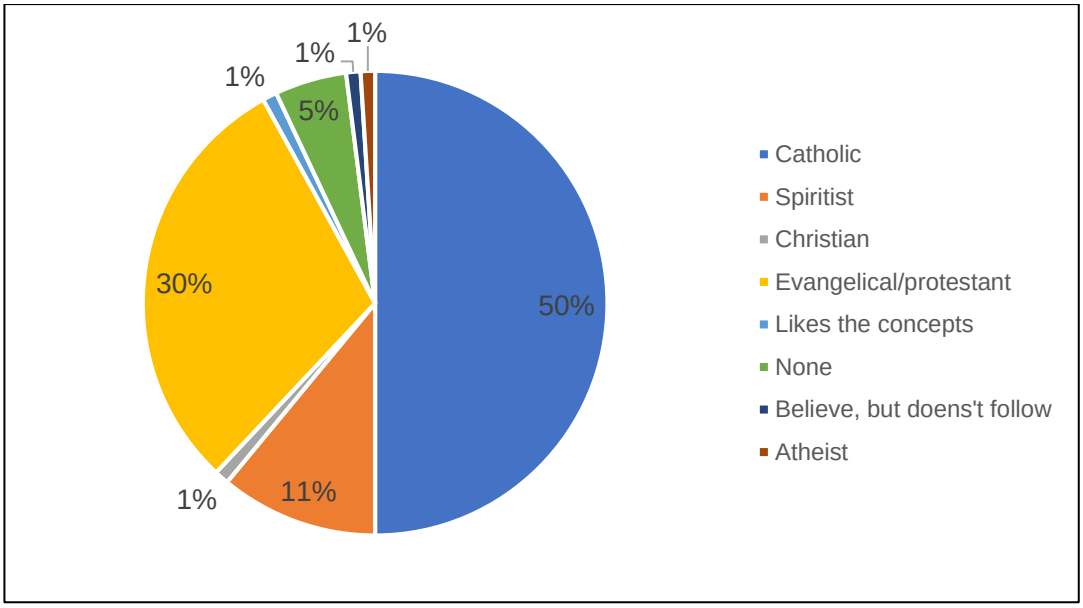
Patients also responded feelings of sadness related to infertility: 45% reported the often or always felt sad and depressed, 32% rarely or never and 23%, sometimes. Also, most patients reported feelings of inferiority to child-bearing persons (71%). Finally, 54% of patients described fatigue.

Although 53% of responded had declared their relationship strengthened due to infertility, 68% indicated a negative impact of infertility on their conjugal life, and 53% admitted difficulty in communicating with their partner about infertility. Most (76%), however, are satisfied with their relationship.

Aside from difficulty in achieving pregnancy, 50% of patients often or always and 21% sometimes feel social pressure to have children and many (69%) patients feel irritation due to infertility; 51% do not feel physical pain.

The general questionnaire provided information about the patients' religion/sect or belief. Most patients declared they followed some religion (figure 1), and most (68%) are engaged in its activities. More than half attend a session, at a temple or equivalent, at least once a week.

Figure 1. Question 27: what is your religion/belief, if any?

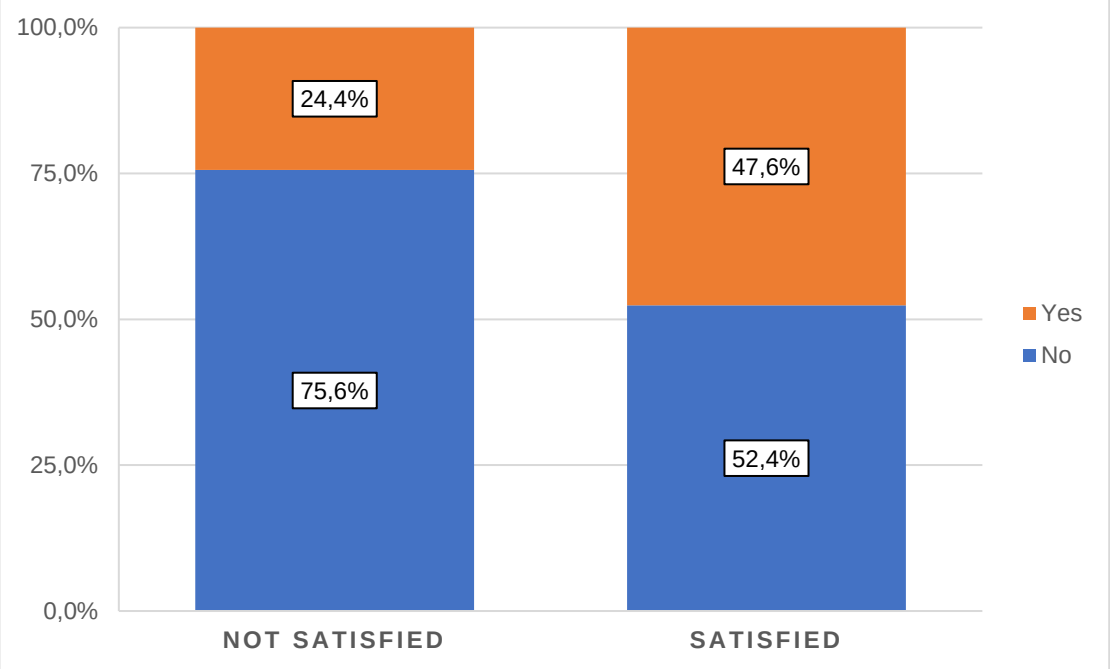


In total, 62% of women did not change their religious habits due to infertility. It was found that 93% of patients resort to prayers or religious texts, and religiousness is important to the well-being of 95% of respondents. Most (71%) patients read religious texts or pray daily and 88% believe prayer helps them face their difficulty in achieving motherhood. Patients related that prayers bring them hope (47%), calm (18%), comfort (12%), tranquility (10%), or inner peace (10%), and 3% feel praying is important for personal growth.

Of the respondents, 66% were in their first treatment, 57% sought or had sought alternative treatments, and 84% changed to a healthier lifestyle.

The results of the analysis of variables that showed a significant difference in the comparison using the chi-square test are presented below. Patients were more satisfied with their quality of life when they had altered their lifestyle ($p<0.05$) (figure 2).

Figure 2. Comparison of change in religious habit in women according to their satisfaction with quality of life.



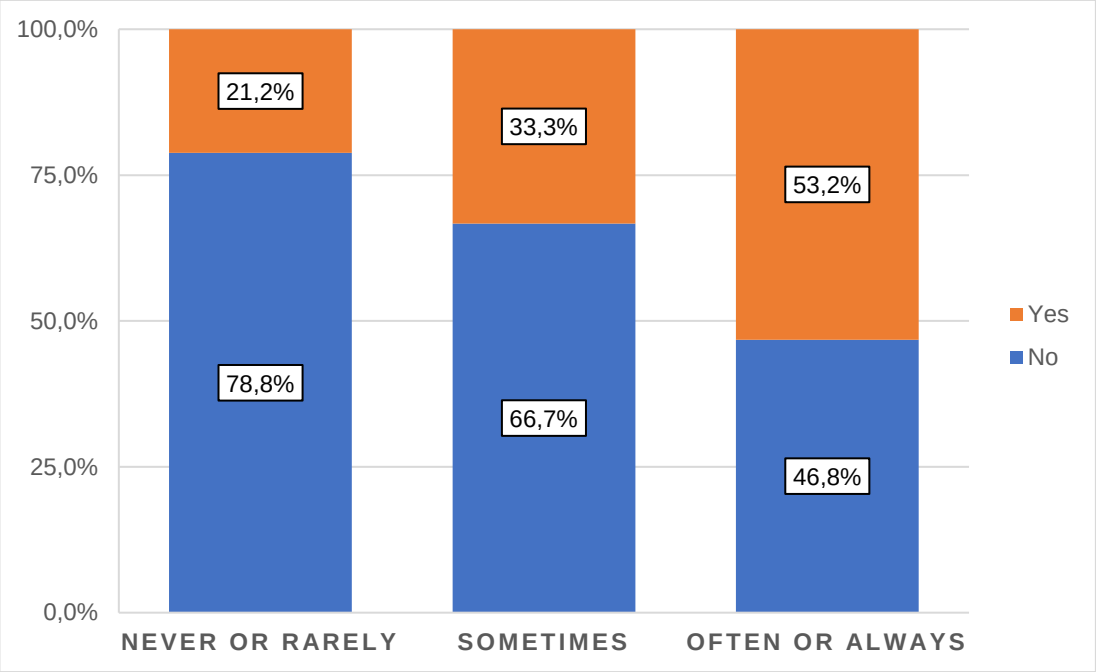
Women more or less satisfied with the support they have been receiving from friends regarding infertility were those who considered religiousness less important than either women who declared to be satisfied or unsatisfied with the support received from friends. These patients also reported more frequently resorting to prayer or religious reading when compared to women who were mostly or completely unsatisfied with support received from friends.

Patients who reported frequently or always feeling jealousy or rancor due to infertility more frequently altered their habit of attending sessions at a temple or equivalent. Patients who never or rarely fluctuated between hope and despair (13.6%) less frequently altered their habit of attending a session at a temple or equivalent. On the other hand, patients who felt isolated more often altered their habit of attending a session at a temple or equivalent, as did patients who related discomfort in social situations.

Patients who reported feeling understood by their families regarding infertility only at times more frequently sought prayer or religious reading, when compared to patients who never or rarely felt understood. Also, patients who reported feelings of sadness or depression often or always more frequently altered their habit of attending

sessions at a religious temple or equivalent when compared to women who rarely felt sad (figure 3).

Figure 3. Comparison of change in habit of attending sessions in a temple or equivalent in women according to their frequency of feeling sad or depressed.



A lower percentage of women declared that infertility negatively impacted their relationships when they participated in any religion, than in those that did not. Patients who reported social pressure to bear children often or frequently were more frequent in their attendance at religious temples or equivalents, and more frequently prayed or read religious texts.

Patients often or always irritated at infertility issues were also more prone to alter their religious habits in terms of frequency of attendance when compared to women seldom or never irritated. Moreover, patients in the first treatment cycle were less prone to alter that habit. Finally, patients that changed to a healthier lifestyle were less prone to attend sessions at a religious temple or equivalent than patients who did not.

Discussion

Achieving motherhood and fatherhood is a central purpose for couples of many different cultures [19] and receiving a diagnosis of infertility goes well beyond physiologic and laboratory issues, leading to a psychological process characterized by changes in habits and religious standards for couples. Women that deal with infertility undergo not only a physical but also an emotional process, before and during infertility treatment [10,20,21].

This study allowed us to observe the effects of infertility on women in a Brazilian cohort, demonstrating infertility leads to medical situations, as well as social, familial, and religious issues. Moreover, we have demonstrated the manner through which patients cope – both emotionally and socially – with infertility, and their changes in habits following diagnosis of infertility. It is important to emphasize that it was appropriate for the analysis of this study to consider religiosity, understanding that spirituality is a personal path in search of meaning to questions about life, and religiosity is related to the individual's belief and religious practice [13].

Thoughts of infertility were associated with disturbance in concentration, and many women found it difficult to move on with their life plans; this, in turn, as was demonstrated by Tamannaifar (2011), could lead to feelings of dissatisfaction in life [22]. Conversely, results showed that women were resilient to negative feelings and leading with difficulty, because, although many felt exhausted due to infertility, most demonstrated confidence in dealing with the problem.

Many studies have demonstrated reduced self-confidence, increased anguish, depression, stress, and sexual dissatisfaction stemming from infertility, directly affecting the quality of life [5,6,23]. In our study, 81% of women admitted to feelings of anguish, and most related they alternated between hope and despair, demonstrating that infertility is associated with emotional distress. Also, many women confirmed social crises, stating they feel discomfort in participating in social events. Karaca and Unsal (2012) discuss this when they state that, in some societies, infertility leads to the incapability of living up to social expectations [24].

It is understood, then, that infertility treatment also encompasses mental health in many couples; as demonstrated, difficulty or impossibility to achieve pregnancy may lead to feelings of anguish or inferiority in child-bearing people. Moreover, many times, couples in treatment for infertility seek support from family or religion, leading to improved resilience and quality of life. Importantly, results in our study demonstrated

women that who were satisfied with their quality of life more frequently altered their habit of attendance at religious temples or equivalents.

In regards to religion, 68.34% of respondents declared to participate in some religious activity, of which 50% were Catholic. Notably, this aligns with the national statistic that approximately 50% of the Brazilian population identifies as Catholic, according to a Datafolha survey conducted in December. Klitzman (2018) stated that a search for religious belief leads to improved outcomes in infertile patients and that this is expected in situations of internal conflicts in patients [25]. In a study in the USA, 51% of respondents were protestant, and 26% Catholic [12]. This occurs because of sociodemographic differences between the USA and Brazil – in the latter, Roman Catholicism is the predominant religion, which explain results in this study [26]. In regard to aspects related to religious practice, 93.23% of participants stated they regularly prayed, and two-thirds that they read daily passages from religious texts. Braga et al. (2019) stated that most patients in their study referred to regular prayer and religious reading, as in our study. The authors infer that decreasing the frequency of prayers negatively associated with a positive outcome while maintaining prayers improved response to ovarian stimulation [16].

It is important to highlight that the possible support that infertile women seek in religiosity/spirituality is a very personal aspect, difficult to measure, but it is noted that the search is a coping mechanism and a different view of reality. Through the interviews carried out in this study, it is suggested that religion and/or spirituality can convey a sense of comfort and, mainly, of hope, making it possible to believe in the main achievement of life, even if there is difficulty in achieving it.

Religiousness was referred to by 95.19% of participants as bearing a positive impact in patients' well-being, and 9 in 10 respondents identified religious belief as a support mechanism for coping with infertility. These results demonstrate a positive role for religiousness in improving patient well-being during treatment, which agrees with findings from Casu et al. (2018), who stated that spirituality and religiousness may provide a positive resource in dealing with infertility, as a means for improved quality of life in these couples [27]. A study with 264 women undergoing infertility treatment identified that the main negative feeling attributed to failure to achieve pregnancy was depression, and that hope was the predominant feeling when they sought medical care [28], as was found in this study.

When we sought to verify patient satisfaction with support from family and friends and with daily prayers, we observed that patients were most satisfied with support from friends in women with daily religious habits. Therefore, frequent religious habits were better prepared to understand their situation and face the sentimental challenges, which is in accordance with Grinstein-Cohen et al. (2017), who identified that patients declared that social difficulty and experience were more painful than treatment itself, and that religiousness improved negative feelings [29]. Collins et al. (2018) further demonstrated the importance of religiousness in facing infertility by showing that three in four patients seek religious or spiritual support, while little over half seek medical care [12].

In regards to feelings of sadness and depression stemming from infertility, when related to attendance in religious temples or equivalents, results from our study demonstrated a gradual increase in the search for religion in women with negative feelings towards infertility, demonstrating these women seek emotional support in spirituality of religiousness. This is in accordance with Romeiro et al. (2017), who described that the adversity these patients underwent produced spiritual needs in these women as a coping mechanism, incorporating religious teachings as tools to overcome these challenges [30]. Likewise, when irritability was correlated to the search for religion, increased attendance was found in women with higher stress levels, similar to the Portuguese study. Tiu et al. (2018) further demonstrated the need for psychological support for patients with increased irritability or stress due to ovulation problems attributed to mood swings [31]. The study also suggests that spiritual or religious measures should be employed in order to reduce stress, thus improving results.

Social pressure to bear a child has been related to religious reading habits and frequency or attendance in religious temples or equivalents, and in both cases, increased social pressures were associated with increased religious habits. Öztürk et al. (2021) agree with the results of this study, demonstrating that social pressure in infertile women is greater than that faced by primiparous fertile women and that this leads to emotional distress with a need for psychological support, either by specialized psychologists or by religious practice [32]. As a socioeconomic counterpoint to the previous findings, a study from Gambia demonstrated similar results regarding psychological pressure and the search for spiritual support, demonstrating that African populations are prone to seek, frequently, solace in biblical texts or religious temples

[33]. Hanselin et al. (2017) stated that infertile patients tend to seek emotional support in religion, but also acknowledge that some religious views may increase psychological pressure in patients [34]. Therefore, spirituality and religiousness may play important positive roles in dealing with social pressure faced by patients; however, they suffer the influence of conservative interpretations, which may lead to increased emotional angst.

Limitations

The present study, as it touches on the personal issues of respondents, has some limitations. First, number of participants was lower than initially planned. We also noted the difficulty of the interviewees when the approach had intimate repercussions, such as marital relationships and family life. In addition, there was no characterization of the studied sample regarding the underlying disease, duration of infertility, male or female factor of infertility, age, and other demographic data. Finally, the relationship between attitudes of coping with infertility was not sufficiently clarified, but the positive result of spirituality could be noted.

It is important to highlight the difficulties encountered in the study as a recommendation for future investigations on the same topic.

Conclusion

This study sought to elucidate how patients cope with infertility. It is noteworthy that religiousness leads to improved adaptive capacity, due to the spiritual quest to decrease suffering brought upon by the absence of children, and by improving quality of life. Sadness, depression, irritability, lower quality of life, and social discomfort were greater in patients with no religious belief, as was a decreased perception of support from family and friends.

While the exact relations may not have been adequately demonstrated, results from this study strongly suggest that spirituality plays an important role in adjusting the psychological aspects of infertile patients.

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5.3 Discussão bioética em busca do princípio da justiça para tratamento a casais inférteis

The search for the principle of justice for infertile couples: characterization of the Brazilian population and bioethical discussion.

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Abstract

Background: Infertility is an increasingly prevalent disease in society and is considered by the World Health Organization to be a public health problem. An important ethical issue arises from the clarification of reproductive rights in a fair and equal way. The objective of this study was to deepen and update the knowledge and discussion about the difficulty of accessing infertility treatments in Brazil.

Methods: A cross-sectional observational study was carried out through the application of an online questionnaire that collected the socioeconomic characteristics of couples and identified how barriers to infertility care affect the most vulnerable populations. We included couples who sought medical assistance to achieve pregnancy at two clinics in the states of São Paulo and Minas Gerais. **Results:** A total of 201 questionnaires were analyzed. Most couples self-declared as white and the average age of wives was 36 years and husbands 38 years. Sixty-five percent (65%) of couples would proceed with the treatment in a different city to which they lived, 37% evaluated as having easy access to a medical specialist only after indication, and more than half of the participants have thought about giving up the treatment due to some difficulty in accessing it. Thirty-nine percent of participants sought more than one medical service to find better reception, 42% of couples sought more than one medical service to define where it would be better financially, and 67.2% referred to the high cost of treatments, that is, financial issues, as a great difficulty in accessing medical services and/or treatment. Although 72.6% of couples considered having a good quality of life, 54.2% admitted that infertility and the search for treatment generated anxiety/stress in the couple's life.

Conclusion: There is a need for public education on reproductive health and for policymakers to raise awareness of the importance of the difficulty that many couples face in seeking treatment to become pregnant, especially in countries with less

financial resources. Indeed, it is commonly accepted that there is a universal human right to access healthcare of appropriate quality as a matter of justice. Discussion of access to reproductive technologies should be considered taking into account the longstanding ethical debate regarding fertility, fecundity, and infertility, as well as reproductive care.
Keywords: Assisted reproduction treatment; bioethics; infertility; justice; principle of justice.

Background

Infertility, defined as the inability of a couple to conceive after one year of regular sexual intercourse and without the use of contraceptive methods [1], can occur due to several factors such as alterations to the male or female reproductive tract or its endocrine control, patient age, and metabolic diseases, among other causes. Infertility directly affects the physical and psychological well-being of patients [2]. It is also noteworthy that infertility has become a significant public health and political problem in the last 25 years [3].

For Mascarenhas et al. (2012), estimates of the worldwide prevalence of infertility indicate that approximately 70 million couples will require medical assistance to achieve pregnancy [4]. Several studies show that infertility is an increasingly prevalent disease in society and, therefore, there is a movement to offer treatment to everyone [5,6]. Although it is still currently necessary to discuss and reinforce reproductive rights, in 1994, during the historic International Conference on Population and Development (ICPD), held in Cairo, the prevention and treatment of infertility were recognized as basic components of rights and care to sexual and reproductive health [7,8].

Furthermore, in 2001, the World Health Organization (WHO) organized a meeting entitled “Medical, ethical and social aspects of assisted reproduction”. At that meeting, in addition to the WHO recommending that infertility be considered a global public health problem, it also recognized it as a disease [9], with a recommendation that infertility management be added to national health education services. It was also recognized that there is a need for affordable assisted reproduction treatments in countries with few resources, using simplified protocols [5].

It is important to admit that infertility and its treatments are the focus of ethical questions about the implications of its use and its accessibility, involving individual,

social, political, legal, economic, religious, and gender issues, thus bringing important debates within the scope of bioethics. In other words, a very important ethical issue is envisaged: the clarification of reproductive rights in a fair and egalitarian way [10]. Therefore, while on one hand, it is the responsibility of the State, as a representation of society, to provide and promote health and the well-being of the population, on the other there are many ethical discussions regarding what are the limits of this responsibility, especially considering the financial burden of treatments (both to individuals and the State), limited resources that lead to election of priorities, novel familiar organizations, and even quality of life of the children and families in vulnerable populations [11].

The inequality gap between having or not having access has been increasing yearly. Studies show that, in the United States, for example, most patients who treat infertility through assisted reproduction protocols are white, have a high educational level and high financial income, and also have access to special health insurance, which includes this benefit. In an analysis of family growth research, it was found that women with infertility who did not have access to evaluation and treatment were the ones with the lowest family income and level of education and without health insurance [12].

It is relevant to point out that, in Brazil, the right to family planning is provided for in the Federal Constitution of 1988 [13], however, a large part of the population remains without access to assisted human reproduction services. Low-income persons with infertility face difficulties in seeking free care or are unable to have this right. Another important factor, according to Martins et al. (2019) is that, in addition to the difficulty of access, many couples are unable to solve the problem of infertility due to the lack of information, with negative consequences in the family and social environment.[2].

According to Inhorn and Patrizio (2015), only 51% of patients with infertility, in countries with few resources, seek medical care, precisely because the service is expensive, and difficult to access, without the possibility of absence from work and travel costs [14]. In recent years there has been an increase in the number of human reproduction clinics around the world, but they are still concentrated in large centers and are accessible to higher-income couples, as mentioned by the European Society of Human Reproduction and Embryology (ESHRE) task force, they are islands of high-tech assisted reproductive treatment in a sea of poverty and medical malpractice

[15,16]. Few couples have equitable and fair access to these services. The financial costs reflect catastrophically on the family budget (exceeding 40% of the family budget) threatening family survival. In this context, they resort to personal loans, take on more work positions, limit themselves to buying food and clothes, and exhaust their savings [14].

In addition to facing difficulties in achieving fatherhood and/or motherhood, the psychosocial consequences of infertility in high-income countries lead to depression, anxiety, loss of self-esteem, relationship difficulties, lower quality of life, and isolation. In low-income countries, especially in some religious beliefs, having children is a family commitment and there is a stigmatization of women, often considered “at fault” for infertility, leading to domestic and psychological violence, marriage dissolution, fear of the husband separating for another wife, disinheritance, and social isolation. This can result in physical and psychological abuse, polygamy, and even suicide [17].

The principle of justice guarantees, or should guarantee, access in an equitable way and can be translated as the equitable, fair, and universal distribution of health-related benefits. In Brazil, the practical application of this principle must allow access to all people, to the use of assisted reproduction techniques, because, health is everyone's individual’s right in addition to being a duty of the State [13]. Thus, on ethical issues, two important points stand out: barriers to access to reproductive care and infertility as a global public health problem [18].

Finally, scientific advances in the medical field and new technologies of assisted human reproduction provide many infertile couples with the realization of the dream of family formation, but there is an increasing incidence of infertility, especially in developing countries, and even more observed where there is socioeconomic inequality, excluding treatment [19]. Thus, the present study aims to address the difficulty of infertile couples in accessing infertility treatments in developing countries, focusing on the essence of the principle of justice.

Methods

A cross-sectional, multicenter observational study carried out through a bibliographic survey and application of an online questionnaire (Google Forms), developed for this study, to couples who sought medical aid to achieve pregnancy at the Oppenheimer Clinic in Santa Rita do Sapucaí (MG) and the Clinic of Fertility and Human Reproduction Gera (São Paulo) between September 2021 and January 2022.

An English translation is provided as supplementary material to this manuscript (supplementary file 1). This study was approved by the Research Ethics Committee (CEP) of the Itajubá School of Medicine (CAAE: 50434521.6.0000.5559). The study consisted of 211 couples, who responded appropriately to the questionnaire. All included participants signed an informed consent form agreeing to participate in the study, and Brazilian National Research Ethics Council guidelines were followed.

The questionnaire was applied to couples over 18 years of age and participants who did not correctly fill out the questionnaire were excluded. Because the study focused on access to care for couples who had been actively trying to conceive without medical assistance previously, homosexual couples and single women were also excluded from this analysis.

Data collection

The bibliographic survey was carried out in PubMed, Google Scholar, LILACS, Web of Science, and SciELO databases and legal decrees. For the research, a narrative review of the literature was carried out including all articles containing the keywords: infertility, bioethics, ethics based on principles, justice, and assisted reproduction treatment published in English from 1998 to the present date.

Preparation and validation of the questionnaire

The two following stages after the literature review were questionnaire elaboration and pilot study validation, as described below.

Elaboration of the questionnaire

The production of the questionnaire items was carried out by researchers in the area of human reproduction and bioethics. Thirty questions were prepared, 24 of which were nominal (yes/no) and 06 were open-ended, with the aim of absorbing knowledge about personal, cultural, economic, and social identity, in addition to identifying the main difficulties of participants in accessing reproductive care. The questions were organized according to the subjects: (a) sociodemographic characteristics of the couple, seeking to know the age, color/race, and level of education of the participants; (b) time of infertility, attempts to become pregnant and cause of infertility; (c) impact of infertility on the couple's life, that is, whether the couple's relationship was strengthened or weakened due to infertility and if they are going through or have gone through moments of anxiety and stress, in addition to pointing out the perception of quality of life; (d) experiences of seeking care and treatment for infertility, identifying

the city where the couples underwent or will undergo the treatment and the difficulties in accessing the necessary treatment, and finally (e) social and economic conditions.

The questionnaire was validated through the elaboration of a scientific article already submitted for publication.

Pilot study

For the pilot study, the online questionnaire was applied to 15 couples over 18 years of age who sought medical treatment for marital infertility and agreed to participate in the study. It was possible to observe whether the participants found it difficult or not to answer the questionnaire and, after statistical analysis, whether the information obtained was satisfactory.

Questionnaire application

After validation in the pilot study, the questionnaire was applied to 211 consecutive couples attending the Oppenheimer clinic between September and December of 2021.

Statistical analysis

For statistical analysis, SPSS 18.0 software for Windows was used. Initially, a descriptive analysis of the data was performed. For continuous numerical variables, mean, standard deviation and 95% confidence interval (95% CI) of the means were presented. For discrete numerical variables, median, interquartile range, minimum and maximum were presented. For frequencies, the percentage and its 95% CI were calculated. Correlation between the variables was verified using Pearson's correlation test (between two continuous numerical variables) or Spearman's correlation test (all other cases). An alpha of 5% was adopted.

Results

The questionnaire was answered by 211 couples who sought medical assistance to achieve pregnancy (104 couples from the Oppenheimer Clinic in Santa Rita do Sapucaí – Minas Gerais and 107 couples from the Clinic of Fertility and Human Reproduction Gera – São Paulo). As they were not considered cases of infertility, homosexual couples (6 questionnaires) and couples where the partner indicated having had a vasectomy (4 questionnaires) were excluded. In this way, a total of 201 questionnaires were analyzed and the results are presented according to the subjects indicated above.

Sociodemographic characteristics of the couple, time of infertility, attempts to become pregnant, and level of education

Starting with the analysis of the age of the partners, it was identified that the average age of the wives was 36.7 years and the average age of the husbands was 38.6 years, observing couples that were still young. The duration of infertility ranged from 6 months to 25 years, with a mean time of 6 years.

Regarding the number of treatments performed to get pregnant, the analysis showed that most couples were making the first or second attempt (Table 1), however, it is important to report that 5.47% of couples showed a lot of distress in the questionnaire when answering that they no longer knew, because they are various, the exact number of attempts.

Table 1. Individual characteristics of respondents to the questionnaire.

Variable	Value
Wife age (years)	
Mean (Standard Deviation)	36.7 (5.30)
95% CI	[35.9; 37.4]
Min – Max	20 – 50
Husband age (years)	
Mean (Standard Deviation)	38.6 (6.96)
95% CI	[37.7; 39.6]
Min – Max	20 – 63
Infertility (years)	
Mean (Standard Deviation)	6.0 (4.29)
95% CI	[5.4; 6.6]
Min – Max	0.5 – 25
Number of treatments (attempts)	
Mean (Standard Deviation)	2.0 (2.05)
95% CI	[1.7; 2.2]
Min – Max	0 – 12

The questionnaire exposed the level of education for both partners of the couple. It was observed that, among the wives (first partner), 19% indicated that they had attended high school, 32% had completed higher education and 38% had postgraduate degrees. Among the husbands (second partner), 36% had an education up to high school, 27% had completed higher education and 20% had a graduate degree.

When analyzing the answers referring to color or race, it was found that most participants (69.2% - wives and 72.6% - husbands) declared themselves white, followed by brown (22% - wives and 20.4% % - husbands) and black (6.5% - wives and 5.5% husbands). Asian races (1.5% - wives and 1.0% - husbands) and indigenous races (1.0% - wives and 0.5% - husbands) were the least indicated options.

In order to characterize the couples, the questionnaire sought to understand whether the participants already had children and whether they knew the cause of infertility. Only 18% of couples already had a previous conception. And, it was shown that in 47.3% of couples, the cause of infertility is female, in 16.4% the cause is male, in 18.4% the cause is considered mixed and in 18% the infertility is without apparent cause.

Experiences of seeking care and treatment for infertility and difficulties in accessing treatment

Interestingly, when asked about the city in which they lived and the city where they would undergo the treatment to achieve pregnancy, 65% of the participants indicated that they would proceed with the treatment in a different city in which they lived, indicating how Brazilian couples search for treatment. Following this reasoning, it was observed that 34.3% of the couples considered having easy access to an assisted reproduction clinic and to infertility treatment options only after searching in a different city in which they lived, and, still, 21.4% indicated difficult access.

The questionnaire showed that 39% of couples considered it easy to access a specialist and medical services to treat infertility, 37% rated it easy to access only after an indication or help, and 24.4% found it difficult to access a specialist doctor. It is important to highlight that more than half of the participating couples (51.7%) have already thought about giving up on treatment due to some difficulty in accessing them.

Although there are adversities, 61.2% of couples felt welcomed in the search for medical services and treatment for infertility, but it still cannot be overlooked that 28% of couples felt welcomed after some frustrating experiences, and 11% were not welcomed. To understand what couples prioritize when choosing a specialized medical service, we asked whether the couple sought more than one service and what motivated them. The answers showed that 39% of the participants sought more than one medical service until they found better care, 42% of the couples sought more than one medical service until they defined where it would be better financially, 14% answered that they did not seek more than one medical service due to lack of services

in their location and only 5.5% did not seek more than one service due to lack of knowledge. Information was also obtained that 77.6% of couples are not aware of free treatment in other countries.

As already indicated in the previous items of the questionnaire, 67.2% of couples demonstrated the high cost of treatments, that is, financial issues, as the greatest difficulty in accessing medical services and/or treatment and 13% of couples pointed to both financial and location difficulties as factors that made access difficult. In this group of participants, only 0.5% of couples think that the greatest difficulty in access involves discrimination.

Impact of infertility on the couple's life and perception of quality of life

Some items of the questionnaire addressed quality of life and personal sentiments experienced by couples. Regarding the impact of infertility on the couple's life, 40% said that the relationship was strengthened by suffering infertility, 21.4% of the couples indicated that the relationship was weakened and 39% did not feel a positive or negative impact on the relationship. Then, 54.2% of couples admitted that infertility and the search for treatment generated anxiety/stress in the couple's life from the beginning, and 33% indicated these feelings only after some treatment attempts. However, despite the moments of anxiety and stress, 24.4% of the participants consider having a great quality of life, 72.6% consider having a good quality of life and only 3.0% of couples consider having a bad quality of life.

Social and economic conditions

We also sought to deepen our knowledge of the socioeconomic status and family income of the participating couples. For 78.1% of couples, the cost of treatment impacted the family budget and 48.3% of couples had to resort to loans or have assets to be able to afford treatment. In addition, 65.2% of the couples found it necessary, after diagnosis and treatment, to wait to obtain financial resources to perform the procedure and 45.3% sought coverage by health plans or the public health system, but they remained helpless.

It was observed that most participating couples have a family income of up to 10,000 reais (1 real – 0,18 €). The option of income between 3,000 and 5,000 was selected by 45% of couples, 31.3% of participants indicated income between 5,000 and 10,000, 8.5% of couples said they had a family income between 10,000 and 15,000, 6.5% of couples have an income between 15,000 and 20,000, only 2% of couples reported having an income of 25,000 or more, and 7% of couples selected an

income range not indicated in the options offered, suggesting a family income below 3,000 reais.

Additionally, couples with a higher income range had better overall self-assessed quality of life ($p=0.010$). Furthermore, it was noted that having better financial conditions is associated with easier access to the assisted reproduction clinic and treatments ($p<0.0001$) and these couples think less about giving up on treatment due to some difficulty in accessing them. ($p=0.021$).

It is important to note that the questionnaire left free space for the participating couples to feel free to enter comments. Most of the comments (34.72%) indicated the immense financial difficulty of accessing and carrying out the treatments suggested by the medical service. Additionally, couples put into words their anxiety about achieving the dream of motherhood/fatherhood and how distressing the whole process can be. For example, some comments indicate: anxiety was an impacting factor among treatment attempts; infertility generates feelings of anguish and frustration; the way is long and painful; the treatment generates many frustrated expectations; my dream is to be a mother, but the treatment is distressing.

Finally, the questionnaire presented the information that several participating couples (71.1%) have friends or acquaintances who also seek treatment to achieve pregnancy and that 27.4% of these friends or acquaintances managed to access treatment with difficulty, and that 11% are still helpless, that is, they have not yet been able to access treatment.

Discussion

Infertility, according to the WHO, is a public health problem and affects about 186 million people worldwide. In Brazil, an estimated 8 million individuals may bear this condition [20,21]. As a treatment, assisted reproduction techniques allow millions of couples who experience infertility the possibility of becoming pregnant, especially in low- and middle-income countries, where we find a higher incidence of infertility [4-6,22].

The results observed in this study allowed us to understand that the narrative of couples who seek pregnancy through assisted reproduction techniques presents important reflections on the experience of undergoing infertility and, also, reflections on the relationship between the difficulties access to treatments and the socioeconomic characteristics of these couples. The reality of working as an infertility

specialist in Brazil, working in the Minas Gerais state countryside, is in line with the responses of the participating couples: a large number of anguished patients are received without a correct investigation of the reason for infertility, and many couples never considered they would be able to commute to larger cities, due to their socioeconomic and cultural level, to carry out this investigation with a specialist. Unfortunately, a limitation was observed in the study by applying a questionnaire because there was no evaluation by a committee of experts before the pilot test.

Indeed, in most countries access to healthcare of appropriate quality is considered a basic and fundamental human right, even a universal human right [23]. It follows that all societies, more or less developed, should promote an intensive debate on the establishment of priorities in healthcare so that it is socially determined, in accordance with the principle of public accountability, if infertility treatments should be offered in the basic healthcare package delivered to all citizens [24]. This is particularly challenging given the many financial burdens already imposed by an increased cost of healthcare (both in developed and in developing nations), as well as novel constitutions of familial relations that render infertility treatment necessary for patients that would not fall under the classic definition of infertility (i.e. after one year of unprotected sexual relations) [11]. Even in countries where infertility treatment is gratuitously offered to infertile patients, there are barriers imposed, such as female age, number of previous children, or number of attempts [25]. It is of utmost importance, then, that such discussions are carried out involving lawmakers, health providers, stakeholders in the access-to-care pipeline, and, especially, patients themselves – especially considering that medical treatment and assisted reproduction are quite often not the only options for managing infertility [25].

After overcoming the access barriers, at first, with adequate care and a confirmed diagnosis, the couples demonstrate satisfaction and are extremely happy, believing that the infertility problem can be solved and, thus, the anguish and anxiety will end. However, from the moment of indication of in vitro fertilization, the costs of the in vitro fertilization treatment (since it is in the private sector), and the need to perform it in another center, a large percentage gives up on having the procedure performed, while other couples responded to be still trying to find financial means for treatment. Only a fraction with higher socioeconomic conditions declared to be able to carry out the treatment immediately.

Corroborating a study by Alon et al. (2021), it was observed that access to assisted reproduction techniques has a cultural inequality, where couples with more schooling (university and graduate studies) were those who managed to resort to specialized services, with 70% of the wives and 47% of the husbands having a higher level of education [26]. A survey by Iba et al. (2021) demonstrated that there is an association between schooling and the search for medical help, exemplifying that people with higher education exhibit more behavior of seeking medical help; in addition, couples with better financial, psychological, social and cultural conditions also present greater search for treatment. Therefore, this group has an awareness of infertility problems, leading to coping with the problem and seeking treatment [27].

Another important finding of the results of the current study is that a large percentage of the wives have a high level of education. Chambers et al. (2013) emphasize that the high level of schooling of wives occurs by postponing pregnancy by concentrating on the profession, and this leads to differences in the pattern of infertility and procreation due to greater purchasing power and facilities in performing in vitro fertilization [28].

As observed, a large percentage of the patients who answered the questionnaire identified themselves as white, showing the racial disparity in access to assisted reproduction treatments [29,30]. According to Butts (2021), black patients begin the search for infertility research 6 to 15 months after white patients do, and they still take a longer time to perform adequate treatment, which negatively reflects on ovarian reserve, leading them to undergo more cycles of treatment with greater costs and lesser successes, characterizing racial inequalities and the absence of equal access to treatments [31].

The result of the study also showed that all care for couples who seek to solve infertility problems in Brazil is carried out in private clinics, directing the treatment to only a portion of the population with greater purchasing power, excluding or creating difficulties for less economically favored couples. The main barrier to accessing treatments suggested by the medical service, according to the study, is financial. Hammarberg and Kirkman (2013) agree and state that the search for financial resources impacts the family budget and possessions, with loans or withdrawal of treatment [16], highlighting the need to make assisted reproduction treatments more accessible through public offerings or supplementary health plans, in pursuit of the principle of justice [32,33].

Another point, demonstrated in the study and also impacting treatment withdrawal, is the difficulty of accessing specialists in the region where they live, limiting specialists and clinics to large centers and many take years for specialized care. This disparity in access to infertility care due to socioeconomic conditions, ethnicity, and geographic area does not guarantee equity, and promoting health is guaranteeing rights and intervening in inequalities in the distribution of goods and services [34,35].

Additionally, infertility is known to cause psychological and social distress such as fear, guilt, depression, marital stress, emotional abuse, intimate partner violence, divorce and partner abandonment, social isolation, economic deprivation, loss of social status, and in some regions (e.g., Africa and Asia), even famine, disease, violence-induced suicide, and loss of dignity in death [16,17,36]. To identify this impact on patient's lives, the questionnaire also addressed questions about the perception of the quality of life of infertile couples, identifying moments of anxiety, anguish, and stress due to infertility and the search for treatment. It was noted that couples manage to maintain hope, but emphasize moments of suffering and pain. In addition to showing stress throughout the process, from getting access to a specialist to completing the treatment, the couples stated that the path to realizing their dream of motherhood/fatherhood was very distressing.

After characterizing the barriers and pointing out the disparities in access to infertility treatments, it became possible to deepen the bioethical argument, in particular, the principle of justice. Questions arise regarding the health of the population and the health system, including its structure, financing, and management of its resources in relation to public policies [37]. In Brazil, the 1988 Constitution establishes health as a social right, but in the current scenario and in the political culture of government practices, the State lacks commitment to universal access to this right [22,33]. Due to this, intervention bioethics seeks to demonstrate the importance of investments and government actions that prioritize healthcare for the less favored classes [32]. Bioethics can contribute to the search for improvements in health and justice conditions [38,39], and this search must be broad, that is, involve social conditions, discrimination, difficulty in accessing information, and to the treatments proposed by the healthcare system.

Thus, according to some researchers, three ethical principles provide an ethical basis for assisted reproduction treatments: the principle of freedom, the principle of utility, and the principle of justice [10,40], which refers to equal treatment and fair

distribution of State funds for health, research, and prevention. However, medical ethics is based on society's moral, religious, and philosophical ideas and principles and is influenced by economics, policies, and laws [41]. This creates tension between the principles of justice and utility, which can result in a disparity in the availability and access to assisted reproductive technology services between the rich and poor [42,43].

It is pertinent to suggest that actions should be implemented to achieve reproductive justice around the world, especially in countries with fewer financial resources. This includes promoting educational programs to prevent infertility before it sets in, early detection of diseases linked to infertility, such as sexually transmitted infections and post-abortion consequences, and reversing global obesity, smoking, and alcohol with its reflection on the hormonal axis of patients [16]. Furthermore, a greater ethical and sociocultural awareness of infertility and the impact of childlessness is warranted, where fatherhood and motherhood are socially obligatory, seeking to support these patients who live in marginality and ostracism, proposing new paths such as adoption or even support for not having children, deconstructing old concepts. Finally, it is of special importance to simplify diagnostic procedures and infertility treatment, bringing lower-cost protocols for ovarian stimulation and IVF procedures, being available and within reach of a larger part of the population. A potential solution is to promote actions that have a public-private partnership with political and governmental support [16].

The Brazilian law 11.935/2009 of mandatory coverage regarding family planning does not state the types of treatment that should be covered. Thus, it is understood that the exclusion of coverage for treatments involving infertility is subject to legal questioning. There was a modification of this law from its original wording in Art. 35-C, by including in the list of mandatory coverage of health plan procedures related to family planning [44]. Even in the face of some judicialization, the judiciary has been more favorable to the derogation of item III of Art. 10 of the Health Insurance Law. Therefore, it is necessary to prioritize public health initiatives to prevent infertility, interventions to reduce costs, and provide specific treatments [5,18].

Affordable infertility treatment can only be successfully introduced in developing countries if sociocultural and economic prerequisites are met and governments can be persuaded to support its introduction. Establishing contacts with the authorities and discussing infertility in public health structures is fundamental [12,36,37]. It also raises the question of contributions from the pharmaceutical and medical industry, with

cheaper equipment, lower cost medication, the manufacture of basic products and laboratories with lower costs, and simplification of procedures so that are accessible, of good quality, and of low economic cost [12,17].

Global access to infertility care in developing countries can only be achieved when it is linked to family planning programs and national and international health strategies. This would entail a shift in the conventional view, which has focused on reducing total fertility rates, to also focus on infertility in patients in need. This would thus emphasize that infertility prevention measures, especially in developing and low-income countries, are essential and must be effective and reach the most vulnerable populations. It is suggested that, in Brazil, these measures are part of a government program within the Sistema Único de Saúde - SUS (Health Single System) [21,36,45].

Finally, since infertility is a disease and is considered by the WHO as a public health problem, ways must be sought for its prevention and treatment, seeking egalitarian health. Therefore, the principles of bioethics are fundamental and should guide the dilemmas faced. The principle of justice establishes a fundamental condition of equity and impartiality, and everyone must be treated ethically and given what is due to them.

Conclusions

Infertility is considered by WHO to be a public health problem with psychological and social repercussions. Its incidence has increased, mainly in regions and countries with less favored socioeconomic and cultural conditions, precisely where access to treatment resources is non-existent. The main barrier to accessing treatment is financial, as the costs are high and have a negative impact on the family budget or even make it impossible to do so. Also, treatments are performed only in private clinics in large centers and patients are forced to move to these regions or give up treatment.

In this study, we tried to find out the conditions of access to infertility treatments in a justice and equity approach. Methodologically this study enrolled only heterosexual couples with clinical diagnosis of infertility. Single women or homosexual couples were excluded because access to reproductive technologies in those cases has a different ethical context. Nevertheless, future studies should also approach this issue. Bioethics, in its critical and interventional role, with a focus on protecting the more fragile members of society, should contribute to the discussion and consolidation of reproductive justice.

The pandemic limited the study because many patients abandoned or postponed treatment during this period. Other studies must be carried out, given the relevance of the theme and the negative impact of experiencing infertility, in order to seek means of justice in the equal treatment of patients.

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6. Discussão

A infertilidade deve ser evidenciada como um transtorno que atinge milhões de casais e que pode afetar a qualidade de vida das pessoas de diversas maneiras. Para esse destaque, a OMS já considera a infertilidade um problema de saúde pública mundial, com incidência em torno de 15% da população **[1]** e uma incidência ainda maior em países de baixa e média renda **[11,14]**. No Brasil, calcula-se que haja em torno de 8 milhões de pessoas inférteis **[23-24]**.

Para muitos casais e algumas culturas, a constituição familiar inclui necessariamente ter filhos e se torna um propósito central de vida **[25]**, dessa forma, o diagnóstico de infertilidade passa das barreiras fisiológicas para repercussões emocionais, podendo levar a mudanças de hábitos de vida e padrões religiosos **[26-28]**. Em especial, a infertilidade, mesmo que a causa não seja feminina, aflige diretamente as mulheres, causando desconsolo também na vida social e familiar. Em muitos casos, em busca de conforto, há um esforço de mudança nos hábitos de vida, na religiosidade e espiritualidade; a religiosidade relacionada com a crença e a prática religiosa e a espiritualidade como um caminho pessoal de busca de sentido para as questões sobre a vida **[29]**.

Como dito, a infertilidade é causa de sofrimento emocional, psicológico e social, como medo, culpa, depressão, estresse conjugal, abuso emocional, violência íntima, divórcio, abandono de parceiro, isolamento social, privação econômica e perda de status social **[12,30-31]**. Para corroborar com os estudos que apontam esse sofrimento e para avaliar o impacto na qualidade de vida dos pacientes inférteis, uma parte do atual estudo aplicou um questionário o qual abordou questões sobre esta percepção de desgaste emocional e também pôde identificar momentos de ansiedade, estresse, sofrimento, dor e um caminho angustiante para a realização do sonho da maternidade/paternidade.

Notou-se que os casais em tratamento buscam apoio familiar e religioso, frequentando templos religiosos ou equivalentes, e com isso, percebem uma melhora na qualidade de vida. Klitzman **[32]** afirmou em seu estudo que a busca da crença religiosa e orações levava a melhores resultados positivos do tratamento. Um estudo de Braga et al. **[33]** afirmou que a maioria dos pacientes tinham prática regular de oração e leitura religiosa e, assim como no presente estudo, mostrou a religiosidade e a espiritualidade como mecanismos de enfrentamento da infertilidade na busca por

conforto e esperança durante o tratamento. O estudo de Casu et al. **[34]** também permitiu esta mesma demonstração positiva do enfrentamento da doença e qualidade de vida dos casais, assim como apontou a depressão como sendo o principal sentimento relacionado ao resultado negativo e que a esperança predomina na busca por assistência médica **[35]**.

Há necessidade de clarificar os termos religiosidade e espiritualidade. Religiosidade refere-se à adesão a práticas, crenças e rituais específicos de uma religião organizada. Inclui aspectos institucionais, doutrinários, rituais e comunitários, oferecendo conforto e orientação através de uma identidade religiosa e uma comunidade de fé **[36]**. Espiritualidade é um conceito mais amplo e subjetivo, envolvendo a busca por significado e propósito na vida, que pode ou não estar associado a uma religião específica. A espiritualidade pode proporcionar paz, propósito e conexão, independente de crenças religiosas, ajudando os indivíduos a encontrar significado em suas experiências e desenvolver resiliência emocional **[37]**.

Grinstein-Cohen et al. **[38]** e Özturk et al. **[39]** concordam que a vivência e dificuldade social pela cobrança de filhos é mais dolorosa que o tratamento, e a religiosidade trouxe uma melhora dos sentimentos negativos, assim como Collins et al. **[40]** mostraram que a procura por apoio religioso ou espiritual era maior que a procura por cuidados médicos. Segundo Romeiro et al. **[41]**, Tiu et al. **[42]** e Hanselin et al. **[43]**, as adversidades e o estresse fazem com que os pacientes busquem apoio psicológico e necessidades espirituais com apoio emocional na religião, superando desafios pelos ensinamentos religiosos.

Em paralelo à avaliação sobre qualidade de vida e religiosidade, o foco principal desse estudo foi se desenvolvendo, e para isso, foi averiguado, em casais que buscaram cuidado médico especializado no interior do Estado de Minas Gerais e na cidade de São Paulo (Brasil), o impacto da infertilidade na vida das pessoas e suas condições socioeconômicas e foram identificadas as principais dificuldades de acesso ao tratamento da infertilidade através de um questionário elaborado e validado para o estudo com coerência metodológica e consistência dos resultados.

Iba et al. **[44]** e Alon et al. **[45]** discorrem sobre a desigualdade cultural de acesso a cuidados médicos e às técnicas de reprodução assistida, como no estudo apresentado, onde os casais com maior escolaridade são os tem esta facilidade. As condições financeira, psicológicas, sociais e culturais também impactam no enfrentamento do problema e na procura do tratamento. Chambers et al. **[46]** enfatiza

a alta escolaridade das esposas pelo adiamento da gestação por conta de crescimento profissional, refletindo no poder aquisitivo e acesso à fertilização *in vitro*, o que foi constatado também no presente estudo.

Há uma dificuldade de acesso a especialistas fora dos grandes centros e onde estão concentradas as clínicas de reprodução assistida, que realizam somente o tratamento no setor privado. Sugere-se ponderar e intervir nas desigualdades socioeconômicas, étnicas e área geográfica para buscar a promoção da saúde e direitos igualitários **[47-48]**. Destaca-se também uma desigualdade racial, onde a maioria das entrevistadas se identificaram como brancas. Butts (2021) coloca que as pacientes negras demoram mais para realizar o tratamento, refletindo em menor sucesso do tratamento e ausência de igualdade de acesso **[49]**.

A principal barreira para acesso aos tratamentos e ao serviço médico especializado, segundo o estudo, é a dificuldade financeira. Hammarberg e Kirkman **[30]** concordam e afirmam que a busca por recursos financeiros impacta o orçamento familiar, com empréstimos ou desistência do tratamento, destacando a necessidade de tornar mais acessíveis os tratamentos de reprodução assistida por meio de ofertas públicas ou planos de saúde suplementar, em busca do princípio da justiça **[50-51]**.

A Constituição do Brasil estabelece que a saúde é um dever do Estado e um direito social, mas as práticas políticas e governamentais carecem de compromisso destas normativas **[51-52]**. A lei brasileira de 11.935/2009 fala de planejamento familiar com cobertura obrigatória, mas não estabelece critérios e os tipos de tratamentos, o que a torna falha em relação a infertilidade e sujeita a questionamento jurídico **[53]**. O acesso aos cuidados de saúde é considerado um direito humano básico e universal **[8]**, e há necessidade de debates públicos para estabelecer prioridades nestes cuidados, de acordo com o princípio da responsabilidade pública, e a infertilidade, considerada uma doença, deve estar dentro dos serviços oferecidos **[54]**.

Isto é particularmente desafiador dados os muitos encargos financeiros já impostos pelo aumento do custo dos cuidados de saúde (tanto nos países desenvolvidos como nos países em desenvolvimento), bem como pelas novas formas de constituições familiares **[55]**. Mesmo em países onde o tratamento da infertilidade é oferecido gratuitamente a pacientes inférteis, existem barreiras impostas, como a idade feminina, o número de filhos anteriores ou o número de tentativas. É da maior importância, portanto, que tais discussões sejam realizadas envolvendo legisladores,

prestadores de cuidados de saúde, partes interessadas no processo de acesso aos cuidados de saúde e, especialmente, os próprios pacientes – especialmente considerando que o tratamento médico e a reprodução assistida muitas vezes não são as únicas opções para gerenciar a infertilidade **[56]**.

As barreiras e desigualdades de acesso ao tratamento da infertilidade é um terreno fértil para atuação da bioética, com foco no princípio da justiça, para uma equidade social, fomentando adequação dos recursos públicos no sistema de saúde **[57]**. Principalmente na bioética de intervenção, contribuindo nas condições de saúde e justiça, com ações e investimentos para as classes menos favorecidas **[50,58-59]**. A justiça social deve ser a base da saúde pública e a busca pela equidade deve ser constante. Infelizmente não temos boas intervenções e esta justiça pretendida não está sendo cumprida **[60]**.

O princípio da justiça deve nortear melhores condições sociais, distribuição de recursos para investigação, prevenção de doenças e tratamentos igualitários pelo sistema de saúde, juntamente com o princípio da liberdade e princípio da utilidade, que são a base para o tratamento da reprodução assistida **[20,61]**. Mas sendo a ética médica baseada em princípios morais, filosóficos, religiosos e por ter repercussões da economia, política e leis **[62]**, mostra um embate entre os princípios da justiça e utilidade no acesso à reprodução assistida pelas classes menos favorecidas **[63-64]**.

A bioética está estreitamente ligada aos direitos humanos, que reconhecem o direito de fundar famílias, conforme a Declaração Universal dos Direitos Humanos de 1948. Contudo, a limitação de recursos públicos pode impedir a oferta de técnicas de reprodução assistida, criando uma tensão entre os princípios da justiça e o direito igualitário ao tratamento. Isso destaca a diferença entre direitos humanos positivos, que os Estados devem fornecer, e negativos, que os Estados não podem obstruir **[61]**.

A fertilização *in vitro* é o último recurso do tratamento para a infertilidade, e promover programas educacionais da prevenção da infertilidade são ações em conjunto na justiça reprodutiva e social. Isto inclui, principalmente em países de baixa renda, na detecção precoce de doenças ligadas a infertilidade como infecções sexualmente transmissíveis, disfunção hormonal, aborto inseguro e outras **[30]**. Promover parceria público-privada, governamental e da indústria farmacêutica na busca por simplificar e baratear os protocolos de estimulação ovariana e tratamentos da infertilidade, para acesso igualitário **[30, 65]**, com compromisso governamental de

metas econômicas e sociocultural a cumprir e discutir a infertilidade na rede básica de saúde pública **[12,31,57,66]**.

Neste contexto podemos ainda incluir na discussão o acesso às tecnologias de reprodução assistida de indivíduos em idade mais avançada, levantando questões éticas significativas. É crucial respeitar o direito desses indivíduos de tomar decisões informadas sobre sua reprodução, baseando-se nos princípios da autonomia, justiça, beneficência e não-maleficência. A discriminação por idade não deve ser o único fator para negar o acesso às tecnologia de reprodução assistida, devendo-se considerar os riscos aumentados de complicações na gravidez para a saúde da mãe e do bebê. Políticas públicas devem estabelecer critérios claros para avaliar a aptidão dos candidatos seniores e oferecer suporte médico e psicológico contínuo para lidar com as possíveis complicações e impactos da parentalidade tardia **[67]**.

Casais homoafetivos também enfrentam barreiras significativas no acesso às tecnologias de reprodução assistida devido a preconceitos sociais e legais. O princípio da justiça remete a igualdade de acesso, combatendo a discriminação baseada na orientação sexual. Respeitar a autonomia desses casais para formar uma família é essencial, proporcionando-lhes as mesmas oportunidades que casais heterossexuais. Políticas públicas devem implementar leis inclusivas e promover campanhas de sensibilização para reduzir o estigma e a discriminação **[68]**.

Indivíduos solteiros, na busca da constituição familiar, devem ter seu direito respeitado, conforme os princípios de autonomia e justiça. Garantir que o estado civil não impeça o acesso às tecnologias de reprodução assistida. Políticas públicas devem oferecer apoio psicológico, social e econômico adequado, além de desenvolver normativas claras que garantam transparência e equidade no acesso, para uma sociedade mais justa e igualitária, respeitando a diversidade dos modelos familiares **[69]**.

A Declaração Universal sobre Bioética e Direitos Humanos **[70]** integra os conceitos de igualdade, justiça e equidade, afirmando que a dignidade e os direitos de todos devem ser respeitados para assegurar um tratamento justo e equitativo. No campo da bioética, é essencial repensar o princípio da justiça com referenciais que superem dicotomias simplistas, como bem-mal e justo-injusto. É necessário diferenciar a justiça de um legalismo jurídico excludente, promovendo uma bioética orientada por direitos humanos universais e legitimidade moral. A bioética justa e democrática deve focar nas razões que justificam juízos de valor e na aplicação

correta das decisões, priorizando o direito de acesso à assistência médica. O conceito de equidade, essencial na distribuição de recursos na saúde pública, foi reforçado após a revisão dos objetivos da OMS em 1996, e implica reconhecer os direitos individuais considerando suas diferenças. Movimentos sociais e debates sobre a distribuição justa de recursos escassos têm sido cruciais na incorporação desse conceito ao campo de saúde **[71]**.

Por fim pode-se apontar algumas limitações deste estudo. Primeiramente, o questionário utilizado para validação não passou por uma revisão de um comitê de especialistas andes do teste piloto, o que poderia ter construído para uma maior precisão e relevância dos dados coletados. No estudo de religiosidade como enfrentamento da infertilidade, o número de entrevistados foi inferior ao programado, o que pode ter limitado a abrangência dos resultados. Devido à natureza sensível do tema, que aborta questões íntimas do relacionamento conjugal e familiar, alguns entrevistados apresentaram dificuldades em responder às perguntas, o que pode ter afetado a qualidade das respostas obtidas.

Além disso, não houve uma caracterização detalhada dos dadosdemográficos, do tempo e da causa da infertilidade, nem se a infertilidade era causada por fatores masculinos ou femininos, o que poderia ter enriquecido a análise e permitido uma compreesão mais profunda dos diferentes contextos enfrentados pelos pacientes. Embora o resultado positivo da religiosidade e espiritualidade no enfrentamento da infertilidade tenha sido evidente, faltou clareza sobre quais atitudes específicas foram tomadas pelos entrevistados para lidar com a situação.

Outro fator limitante foi o impacto da pandemia de COVID-19, que resultou no adiamento ou abandono de muitos tratamentos, afetando a continuidade do estudo e possivelmente os resultados finais. Essa situação ressalta a necessidade de futuras pesquisas que possam ser realizadas em períodos mais estáveis, fora do contexto pandêmico, para obter uma visão mais precisa e compreta sobre o tema.

Muitas destas limitações são comuns em artigos científicos, mas é importante referir as limitações de maneira a buscar formas de superá-las. Por exemplo, para validar o questionário, poderia ser feita uma revisão por um comitê de especialistas e sua aplicação e sua aplicação em outros estados do Brasil, a fim de verificar a consistência dos resultados em diferentes contextos. Estudos qualitativos também podem ser adotados par arecolher dados mais profundos sobre as experiências e vivências dos casais inférteis, permitinto uma compreensão mais abrangente e

detalhada das sua dificuldades e estratégias de enfrentamento. Essas abordagens podem enriquecer futuras pesquisas e contribuir para um desenvolvimento de políticas públicas mais eficazes e equitativas no campo da reprodução assistida.

O estudo cumpriu seu objetivo no sentido de mostrar os pontos onde há maneiras de ações para buscar, junto aos pacientes com infertilidade, uma justiça ao acesso no diagnóstico e tratamento. São necessários outros estudos po conta da importância da problemática estudada e reflexo nas populaões mais vulneráveis.

7. Conclusão

A presente tese teve como objetivo aprofundar e atualizar o conhecimento e a discussão sobre a dificuldade de acesso aos tratamentos de infertilidade nos países em desenvolvimento, com foco no princípio da justiça.

Principais Conclusões:

1. **Características Socioeconômicas dos Casais com Infertilidade:** O estudo revelou que o acesso aos tratamentos de infertilidade nos estados de São Paulo e Minas Gerais é predominantemente restrito a casais com maior poder aquisitivo, nível de escolaridade mais elevado e pertencentes à raça branca. Esta desigualdade evidencia uma falta de equidade no acesso aos cuidados de saúde reprodutiva, refletindo um problema sistêmico que requer atenção urgente.
2. **Barreiras ao Acesso aos Cuidados de Infertilidade:** As principais barreiras identificadas são de natureza financeira e geográfica. No Brasil os serviços de reprodução assistida são oferecidos majoritariamente pelo setor privado, com custos elevados que impactam negativamente o orçamento familiar, muitas vezes tornando o tratamento inacessível. Além disso, a concentração de especialistas e clínicas em grandes centros urbanos limita o acesso para casais que vivem em regiões periféricas, exacerbando as desigualdades **[12]**.
3. **Impacto da Infertilidade na Qualidade de Vida e Religiosidade como Mecanismo de Enfrentamento:** A infertilidade tem repercussões significativas na qualidade de vida dos pacientes, afetando-os psicologicamente e socialmente. Muitos casais recorrem à religiosidade e à espiritualidade como mecanismos de enfrentamento, demonstrando que tais práticas podem melhorar a capacidade adaptativa e proporcionar um ajuste psicológico positivo, aliviando o sofrimento associado à infertilidade.

Implicações para a Comunidade Científica e Clínica:

Esta tese sublinha a necessidade de políticas de saúde pública que garantam acesso igualitário aos tratamentos de infertilidade. Ações governamentais devem

focar não apenas na disponibilidade dos tratamentos, mas também em medidas preventivas para reduzir a incidência de infertilidade. Além disso, promover parcerias público-privadas pode ajudar a diminuir os custos dos tratamentos, tornando-os mais acessíveis a uma maior parte da população **[53]**.

Sugestões para Pesquisas Futuras:

1. **Ampliação do Escopo Geográfico:** Estudos futuros devem incluir uma variedade maior de regiões e contextos socioeconômicos para fornecer uma visão mais abrangente sobre as barreiras ao acesso aos tratamentos de infertilidade.
2. **Intervenções de Políticas Públicas:** Pesquisas devem investigar a eficácia de diferentes intervenções de políticas públicas destinadas a melhorar o acesso aos tratamentos de infertilidade, especialmente em regiões de baixa renda.
3. **Impacto Psicológico e Social:** Estudos adicionais são necessários para explorar mais profundamente o impacto psicológico e social da infertilidade, incluindo a eficácia de diferentes mecanismos de enfrentamento, como a religiosidade e espiritualidade.
4. **Inovação e Acesso Tecnológico:** Investigar novas tecnologias e abordagens inovadoras que possam reduzir os custos e aumentar a acessibilidade dos tratamentos de reprodução assistida.

Dessa forma, as barreiras e desigualdades no acesso aos tratamentos de infertilidade representam um terreno fértil para a atuação da bioética. Em seu papel crítico e interventivo, a bioética deve focar na proteção dos grupos vulneráveis e contribuir para a discussão e consolidação da justiça reprodutiva. A temática é pouco debatida na literatura, havendo escassez de artigos dedicados ao assunto **[58]**. Portanto, novos estudos são imprescindíveis, dada a relevância do tema e o impacto negativo da infertilidade, a fim de promover justiça e igualdade no tratamento dos pacientes.

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ANEXOS

ANEXO 1

FACULDADE DE MEDICINA DE ITAJUBÁ - FMIT

PARECER CONSUBSTANCIADO DO CEP

DADOS DA EMENDA

Título da Pesquisa: Infertilidade: impacto na religiosidade e qualidade de vida das mulheres.
Pesquisador: DRAUZIO OPPENHEIMER
Área Temática:
Versão: 3
CAAE: 24957519.3.0000.5559
Instituição Proponente: CENTRO DE CIENCIAS EM SAUDE DE ITAJUBA S.A
Patrocinador Principal: Financiamento Próprio

DADOS DO PARECER

Número do Parecer: 4.424.417

Apresentação do Projeto:
Apresenta-se estudo observacional sobre infertilidade e fatores intervenientes.
A infertilidade é definida como a ausência de gravidez após 12 meses de relações sexuais regulares sem proteção. A cada ano, as taxas de infertilidade vêm aumentando, seja por patologias físicas ou por protelar a gestação (onde ela busca primeiro a estabilização profissional), situação em que a quantidade e qualidade de oócitos está comprometida. Ao procurar engravidar e deparar com a infertilidade ocorrem vários reflexos negativos no relacionamento conjugal, assim como nas questões pessoais das mulheres, levando ao estresse, angústia e depressão. Essa situação afeta diretamente a qualidade de vida. Muitos, por questões financeiras não tem como procurar auxilio especializado, e outros não o fazem por receio do resultado negativo do tratamento. É frequente, pela facilidade das redes sociais, a procura por grupos que estejam vivenciando a mesma situação, como forma de troca de experiências, apoio e incentivo. Além disso, a mulher também busca conforto na religiosidade e espiritualidade, usando a fé como forma de enfrentamento e superação das consequências negativas. Trata-se de um estudo transversal, com questionário pré formulado entregue às pacientes em uma clínica especializada, que busca avaliar o impacto da infertilidade na qualidade de vida e religiosidade das pacientes.

[Cópia RESUMO do arquivo PB_Informações_Básicas]

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FACULDADE DE MEDICINA DE ITAJUBÁ - FMIT

Continuação do Parecer: 4.424.417

Objetivo da Pesquisa:

Verificar, em uma coorte de mulheres brasileiras em tratamento para infertilidade conjugal, se há relação entre religiosidade e qualidade de vida.

Avaliação dos Riscos e Benefícios:

Riscos: Risco mínimo

Benefícios: O projeto de pesquisa visa, do ponto de vista da paciente com infertilidade, procurar entender melhor as alterações apresentadas, não somente do ponto de vista físico da patologia, mas em uma maneira geral para que a paciente possa ser melhor compreendida e ter auxilio durante seu tratamento necessário.

Comentários e Considerações sobre a Pesquisa:

Estudo observacional, transversal, a partir de entrevistas.

Considerações sobre os Termos de apresentação obrigatória:

Vide campo "Conclusões ou Pendências e Lista de Inadequações".

Recomendações:

Vide campo "Conclusões ou Pendências e Lista de Inadequações".

Conclusões ou Pendências e Lista de Inadequações:

Apresenta-se relatório com informações sobre encerramento da pesquisa por conta da Pandemia COVID-19. Intercorrências não foram relatadas, além dos desafios sobre o número amostral.

Considerações Finais a critério do CEP:

Este parecer foi elaborado baseado nos documentos abaixo relacionados:

Tipo Documento	Arquivo	Postagem	Autor	Situação
Informações Básicas do Projeto	PB_INFORMAÇÕES_BÁSICAS_1609763_E1.pdf	31/10/2020 17:44:43		Aceito
Outros	RELATORIO_SEMESTRAL.pdf	31/10/2020 17:43:02	GIOVANNA CAZELATO MENIN DA FONSECA	Aceito
Projeto Detalhado / Brochura Investigador	PROJETO_PB_ok.doc	05/12/2019 14:29:00	DRAUZIO OPPENHEIMER	Aceito
Folha de Rosto	folha_de_rosto.pdf	04/11/2019 15:44:25	DRAUZIO OPPENHEIMER	Aceito
TCLE / Termos de	TCLE.docx	04/11/2019	DRAUZIO	Aceito

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FACULDADE DE MEDICINA DE ITAJUBÁ - FMIT

Continuação do Parecer: 4.424.417

Assentimento / Justificativa de Ausência	TCLE.docx	15:39:41	OPPENHEIMER	Aceito

Situação do Parecer:
Aprovado

Necessita Apreciação da CONEP:
Não

ITAJUBA, 26 de Novembro de 2020

Assinado por:
Paulo José Oliveira Cortez
(Coordenador(a))

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ANEXO 2

FACULDADE DE MEDICINA DE ITAJUBÁ - FMIT

PARECER CONSUBSTANCIADO DO CEP

DADOS DO PROJETO DE PESQUISA

Título da Pesquisa: A busca pelo princípio da justiça aos casais inférteis: Caracterização da população brasileira e discussão bioética

Pesquisador: DRAUZIO OPPENHEIMER

Área Temática:

Versão: 1

CAAE: 50434521.6.0000.5559

Instituição Proponente: CENTRO DE CIENCIAS EM SAUDE DE ITAJUBA S.A

Patrocinador Principal: Financiamento Próprio

DADOS DO PARECER

Número do Parecer: 4.920.415

Apresentação do Projeto:

A infertilidade conjugal atinge aproximadamente 15% da população mundial. Mais do que a falha em atingir a gestação, a infertilidade gera um momento de angústia, estresse e ansiedade, podendo ameaçar um dos principais planos de um casal: a paternidade. Adicionalmente, a medicina
reprodutiva reconhece o difícil acesso vivenciado por alguns casais que buscam tratamento médico e, embora haja discussões e programas para diminuir as barreiras, ainda hoje observa-se disparidades ao acesso aos tratamentos de reprodução assistida entre países de alta renda e os países em desenvolvimento, os quais apresentam altas taxas de infertilidade. Os países-membro da Nações Unidas buscam tornar a bioética mais aplicada e comprometida com as populações mais vulneráveis, procurando exercer a justiça em oferecer acesso ao serviço médico e tratamento de infertilidade a todos. Com isso, é importante destacar o conceito do principialismo no âmbito da medicina reprodutiva e questionar sobre como praticar a justiça com a adversidade de tecnologias cada vez mais complexas e caras, ainda, refletir como ainda nos dias atuais a oportunidade de buscar a maternidade ou paternidade com auxílio médico é exclusiva. Por fim, nota-se a lacuna existente entre a idealização dos princípios bioéticos, especificamente a justiça, e a acessibilidade ao tratamento de infertilidade por diversos pacientes, assim como a possibilidade de escolha do tipo de tratamento, tornando-se extremamente importante a discussão ética e médica sobre reconhecer a infertilidade como uma doença que atinge uma parcela significativa da

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população mundial, identificar e caracterizar esses pacientes e, em adição, buscar um planejamento de atendimento e disponibilidade aos tratamentos abrangendo a diversidade de pacientes, cumprindo assim o conceito do principialismo.

[Cópia do campo resumo do arquivo PB_INFORMAÇÕES_BÁSICAS]

Objetivo da Pesquisa:

Objetivo Primário:

O presente estudo busca aprofundar e atualizar o conhecimento e a discussão sobre a dificuldade de acesso aos tratamentos de infertilidade em países em desenvolvimento, colocando em foco a essência do principialismo.

Objetivo Secundário:

•Identificar as características socioeconômicas de casais com infertilidade atendidos em cidades de São Paulo e Minas Gerais - Brasil;

•Identificar como as barreiras aos cuidados de infertilidade afeta as populações mais vulneráveis.

Avaliação dos Riscos e Benefícios:

Riscos:

(X) Risco mínimo (consequências que não interferem nas atividades físicas e/ou intelectuais de rotina)

Benefícios:

Há uma lacuna existente entre a idealização dos princípios bioético, especialmente a justiça, e a acessibilidade ao tratamento da infertilidade por diversos paciente, assim como a possibilidade de escolha do tipo de tratamento de infertilidade por diversos pacientes, tornando-se extremamente importante a discussão ética e médica sobre reconhecer a infertilidade como uma doença que atinge uma parcela significativa da população mundial. Buscar um planejamento de atendimento e disponibilidade aos tratamentos abrangendo a diversidade de pacientes, cumprindo assim o conceito do principialismo.
[Cópia do campo riscos e benefícios do arquivo PB_INFORMAÇÕES_BÁSICAS]

Comentários e Considerações sobre a Pesquisa:

O presente estudo busca aprofundar e atualizar o conhecimento e a discussão sobre as dificuldades de acesso aos tratamentos de infertilidade,colocando em foco a essência do principialismo. Identificar as características socioeconômicas e identificar as barreiras aos

cuidados de infertilidade dos casais com infertilidade. Será utilizado um questionário pré-formulado que será enviado através da ferramenta “google forms”: https://forms.gle/SnkgPaLNUrDohdMw9 para os participantes. Será realizado um estudo observacional transversal multicêntrico. A pesquisa será realizada por meio de levantamento bibliográfico e questionário pré-formulado. Para análise estatística, será utilizado o software SPSS 18.0 para Windows. Inicialmente, será realizada análise descritiva dos dados. Para variáveis numéricas contínuas, será apresentado média, desvio padrão e intervalo de confiança de 95 % (IC 95%) das médias. Para variáveis numéricas discretas, será apresentado mediana, intervalo interquartil, mínimo e máximo. Para frequências, será calculada a porcentagem e seu IC 95%. Será verificado correlação entre as variáveis utilizando o teste de correlação de Pearson (entre duas variáveis numéricas contínuas) ou de Spearman (todos os outros casos). Será adotado um alfa de 5.
Será realizado um estudo observacional transversal multicêntrico. A pesquisa será realizada por meio de levantamento bibliográfico e aplicação de questionário online (Google Forms) aos casais que procurarem a Clínica Oppenheimer em Santa Rita do Sapucaí (MG) e a Clínica de Fertilidade e Reprodução Humana Gera (SP). O estudo terá início após aprovação da submissão ao Comitê de Ética em Pesquisa (CEP) da Faculdade de Medicina de Itajubá. Será aplicado um questionário aos casais maiores de 18 anos que buscam tratamento médico para a infertilidade conjugal e que aceitarem participar do estudo. O questionário irá conter perguntas para levantar as informações levantadas por este estudo e o que impacta ou impactou durante o tratamento. O questionário passará por uma etapa piloto com aproximadamente 15 casais para validação.

Considerações sobre os Termos de apresentação obrigatória:
Inserir: Vide campo "Conclusões ou Pendências e Lista de Inadequações".

Recomendações:
- Considerando que o presente protocolo identifica que a coleta de dados se dará por meio de questionário online, solicita-se que a modalidade de registro indique, de forma DESTACADA, ao participante de pesquisa a importância de guardar em seus arquivos uma cópia do documento de Registro de Consentimento e/ou garantindo o envio da via assinada pelos pesquisadores ao participante de pesquisa.

- Verificar acesso pelo Link (a análise foi realizada através das informações contidos no Projeto Detalhado.

FACULDADE DE MEDICINA DE ITAJUBÁ - FMIT

Continuação do Parecer: 4.920.415

Conclusões ou Pendências e Lista de Inadequações:

PP Aprovado.

Considerações Finais a critério do CEP:

De acordo com a Resolução CNS nº. 466/2012, item XI.2, os relatórios parcial e final deverão ser enviados (submetido para avaliação do CEP) utilizando-se da opção "Enviar Notificação". Essa opção está descrita no manual "Submeter Notificação" disponível na Central de Suporte (canto superior direito do portal www.saude.gov.br/plataformabrasil. Na página do CEP da FMIT os pesquisadores encontram modelos para a elaboração dos relatórios -https://www.fmit.edu.br/sites/cep/documentos-e-resolucoes

Para mais informações sobre envio de notificação na Plataforma Brasil, acessar: https://www.youtube.com/watch?v=blYK_0luq4A&feature=emb_logo

Este parecer foi elaborado baseado nos documentos abaixo relacionados:

Tipo Documento	Arquivo	Postagem	Autor	Situação
Informações Básicas do Projeto	PB_INFORMAÇÕES_BÁSICAS_DO_PROJETO_1774060.pdf	14/06/2021 11:41:15		Aceito
TCLE / Termos de Assentimento / Justificativa de Ausência	TCLEprojeto.doc	14/06/2021 11:40:07	DRAUZIO OPPENHEIMER	Aceito
Projeto Detalhado / Brochura Investigador	Projetodepesquisadetalhado.docx	14/06/2021 11:39:53	DRAUZIO OPPENHEIMER	Aceito
Orçamento	Orcamento.docx	14/06/2021 11:39:16	DRAUZIO OPPENHEIMER	Aceito
Declaração de Instituição e Infraestrutura	direcaotecnica.pdf	14/06/2021 11:38:24	DRAUZIO OPPENHEIMER	Aceito
Cronograma	Cronograma.docx	14/06/2021 11:37:56	DRAUZIO OPPENHEIMER	Aceito
Brochura Pesquisa	Brochurapesquisacompleta.docx	14/06/2021 11:37:31	DRAUZIO OPPENHEIMER	Aceito
Folha de Rosto	folhaderosto.pdf	14/06/2021 11:35:44	DRAUZIO OPPENHEIMER	Aceito

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FACULDADE DE MEDICINA DE ITAJUBÁ - FMIT

Situação do Parecer:
Aprovado

Necessita Apreciação da CONEP:
Não

ITAJUBA, 20 de Agosto de 2021

Assinado por:
Paulo José Oliveira Cortez
(Coordenador(a))

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ANEXO 3

Oppenheimer et al. Reproductive Health (2023) 20:183
https://doi.org/10.1186/s12978-023-01724-7

Reproductive Health

RESEARCH Open Access

Access to infertility care in Brazil: validation of a questionnaire for a bioethical discussion

Drauzio Oppenheimer[1,2*], Christiane Peres Caldas[2], Francisca Rego[2] and Rui Nunes[2]

Abstract

Background The World Health Organization characterizes infertility as a disease since 2009; however, in many countries, reproductive health is not prioritized. Characterizing a target population and knowing the barriers to accessing reproductive care may allow for a broadening of the discussion on how to provide equal opportunities. The objective of this study was to develop and validate a questionnaire that seeks to identify socioeconomic and cultural characteristics of Brazilian infertile couples to open the discussion on the principle of fair access to health.

Methods (1) literature review in the main databases, (2) questionnaire elaboration by researchers within the areas of human reproduction and bioethics, concerned with content adequacy and comprehension, using the Google Forms online platform, (3) pilot study - the questionnaire was applied to 54 couples, over 18 years of age, that were seeking treatment for infertility and accepted to participate in the study and (4) statistical analysis - for continuous numerical variables, mean, standard deviation and 95% CI of the means were presented. For discrete numerical variables, median, interquartile range, minimum and maximum were presented.

Results Forty-four questionnaires were fully completed and with adequate answers. The questionnaire proved to be objective and easy to understand. It was possible to obtain information on education, race of the couple, the impact of infertility on the couple's life, socioeconomic conditions, and the main difficulties in accessing medical care for treatment of infertility.

Conclusion The questionnaire proved to be feasible in collecting appropriate information to characterize a target population and the only limitation was that there was no academic expert evaluation prior to the pilot test.

Plain language summary

Although infertility has been considered a disease by the World Health Organization since 2009, there is still much disparity in access to care and in governmental policies to guarantee patients may be treated, especially in developing countries. In this study, we sought to raise awareness to this issue in Brazil, by validating a questionnaire that allows patients to express their difficulties in accessing treatment. We hope this allows for future studies that will, in time, lead to development of policies to guarantee access to reproductive care in a developing country.

Keywords Infertility, Medical infertility access, Questionnaire validation

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Background

The principles set forth in 1995 by the World Health Organization (WHO) in regard to reproductive health state that women have a right to physical, mental, and social welfare [1]. It is therefore imperative to provide appropriate access to reproductive care and support

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patients that seek to restore fertility and raise their own family [2, 3]. However, it has also been recognized that there are geographic, social, economic, political, and biological barriers that impede access to care to a large portion of men and women [4]. This leads to the need to provide better opportunities and access to reproductive medicine for patients that seek low- or high-complexity fertility treatment [5].

Many meetings – such as the 2015 American Society for Reproductive Medicine (ASRM) annual meeting, with participants from throughout the globe – have been organized to propose a strategic plan that aims at providing access to care to all infertility patients. A central point towards achieving this goal and to increase populational access to specialized care and treatments in reproductive medicine is to adequately characterize the population that faces these barriers and to understand the reasons that limit access to reproductive care [5].

Although the WHO classifies infertility as a disease since 2009 [6, 7], many specialists note that infertility—and reproductive health—is still not prioritized [8], leading to a lack of assistance or to excessive requirements to include treatments in public or private health systems [9]. Moreover, cost of treatment, age discrimination, ethnic and racial diversity, social and economic inequality, and religious and cultural beliefs further worsen conditions for these patients. Physical access is also of concern, because there is geographic concentration of practitioners and specialized assisted reproduction clinics, which further hinders patients in accessing care for infertility [5].

Although there is mobilization by medical and scientific societies and patient advocacy groups that have demonstrated disparities in access to medical treatment for infertility [5, 10], it is noteworthy that current opportunities in achieving medical assistance for maternity or paternity are largely excluding [11]. Taken together, this information demonstrates that there aren't trustworthy data regarding current number of infertile men and women in the Brazilian population, and that these data may be skewed in the vulnerable population. Understanding this, and gathering demographic and socioeconomic data from vulnerable patients by means of a questionnaire, which allows the capture of participant feelings and opinions, may provide data so as to tailor policies and treatments in a more equanimous manner, as well as to increase ethical discussion regarding inequality in access to care.

Thus, in order to understand current limitations in access to care for a portion of the Brazilian population and to study possibilities in exercising their right to reproductive health and family planning, the objective of this study was to elaborate and validate a questionnaire that seeks to identify socioeconomic characteristics of infertile Brazilian couples and to identify how current barriers to infertility care affect vulnerable populations.

Materials and methods

An observational study to develop a questionnaire and determine difficulties in access to reproductive care for infertile couples in the states of Minas Gerais and Sao Paulo – Brazil was carried out. An ongoing validation study is underway to broaden and update knowledge on difficulty in access to care in developing countries. A pilot study was thus conducted to validate this questionnaire. Institutional review board approval was obtained from the Itajubá School of Medicine (project number 4.920.415). Only couples seeking to achieve paternity/maternity were included.

In order to develop and validate the questionnaire, four steps were carried out: (i) literature review, (ii) questionnaire elaboration, (iii) pilot study, (iv) statistical analysis.

Literature review was carried out using the Pubmed, SciELO, LILACS, and Web of Science databases, to generate content for questionnaire elaboration. Search terms used were: access to care, assisted reproduction, biomedical ethics, fertility care, infertility and infertility questionnaire. No constraints were set for publication date or language.

The questionnaire was elaborated using Google Forms by researchers within the areas of human reproduction and bioethics, concerned with content adequacy, objectivity, clarity, ease of reading, and comprehension. Twenty-three questions were elaborated, eighteen in a nominal response scale and five open questions that aimed at identifying personal, cultural, socioeconomic identities, and the main difficulties in access to reproductive care. Questions were separated in: couple characteristics, duration of infertility, impact of infertility on couple's life, personal experiences when seeking reproductive care and treatment, and socio-economic characteristics.

The questionnaire was applied to fifty-four couples, over 18 years of age, seeking medical treatment for conjugal infertility who consented to participate in the study. Data were collected by via Google Forms questionnaire.

It was possible to observe whether the participants found it difficult or not to answer the questionnaire and, after statistical analysis, whether the information obtained was satisfactory.

Statistical analysis was carried out using SPSS 21.0 for Windows®. Initially, a descriptive analysis of the data was performed. For continuous numerical variables, mean, standard deviation and 95% confidence interval (95% CI) of the means were presented. For discrete numerical variables, median, interquartile range, minimum and

Table 1 Observed inconsistencies in the questionnaire

Which city will the couple perform the treatment?	How long is the couple's infertility?	What were the number of attempts (treatment) to get pregnant?
14 years	homosexual couple	NO ANSWER
We haven't chosen yet	I don't have eggs	Infinite
	Vasectomy	Several
	undetermined	I don't know the exact number

Table 2 Age of the partners and duration of infertility

Variable	Value
Wife age (years)	
Mean (Standard Deviation)	36.5 (5.552)
95% CI	34.98; 38.02
Min – Max	24–48
Husband age (years)	
Mean (Standard Deviation)	38.83 (7.368)
95% CI	36.85; 40.84
Min – Max	24–53
Duration of infertility (years)	
Mean (Standard Deviation)	6.290 (4.102)
95% IC	5.124; 7.456
Min – Max	1–20

Table 3 Demographic data

Variable	Wife	Husband
Education		
Elementary school	0	4 (7.4%)
High school	15 (27.8%)	19 (35.2%)
College degree	18 (33.3%)	16 (29.6%)
Incomplete college education	4 (7.4%)	5 (9.3%)
Post-graduation	17 (31.5%)	10 (18.5%)
None of the alternatives	0	0
Color or race		
Asian	0	2 (3.7%)
White	37 (68.5%)	39 (72.2%)
Indigenous	0	0
Brown	16 (29.6%)	11 (20.4%)
Black	1 (1.9%)	2 (3.7%)

maximum were presented. For frequencies, the percentage and its 95% CI were calculated. Correlation between variables was verified using Pearson's correlation test (between two continuous numerical variables) or Spearman's correlation test (all other cases). An alpha error of 5% adopted for the study.

Results

Fifty-four questionnaires were administered over a period of two months. Ten questionnaires were incomplete or with unsatisfactory answers and 44 questionnaires were fully completed and with adequate answers to the questions. Only 3 items led to no response or inconsistent answers, which were about treatment location, duration of infertility, and number of previous treatments (Table 1).

Age and duration of infertility data are presented in Table 2. Analysis of the partners showed that the lowest age for the wives was 24 years old and the highest age was 48 years old. In relation to the husbands, the youngest was 24 years old and the oldest was 53 years old. The time of infertility varied between 1 year and 20 years, as shown in the table below. Most wives were older than 35 years and husband age was normally distributed ($p > 0.05$ in a Kolmogorov Smirnov test). Most patients reported less than 10 years of duration of infertility.

Demographic data are presented in Table 3. In total, 33% of wives and 29.6% of husbands had completed higher education, and all wives reported at least having completed high school education. Most wives (68.5%) and husbands (72.2%) were self-declared white. Regarding the number of previous treatments, three couples indicated numerous attempts and, therefore, were unable to inform the exact amount. Only 2 couples indicated more than 5 attempts and most of the participating couples (56%) indicated 1 or 2 attempts. A total of 13% of couples had previous paternity/maternity. Moreover, 50% of couples presented with a female cause of infertility, 14.8% a male cause, 18.5% a mixed cause, and 9 couples presented with unexplained infertility (Table 4).

When asked about how infertility has impacted the couple's life, 38.9% stated that infertility strengthened the couple's relationship, 18.5% stated that the relationship had weakened and 42.6% believed that infertility did not impact the relationship either positively nor negatively. Regarding anxiety or stress due to infertility and the search for treatment, most couples (51.9%) admitted moments of anxiety from the beginning and 31.5% said they developed anxiety only after treatment attempts.

Table 4 Number of previous treatments, infertility cause and previous paternity/maternity

Question. Will the couple undergo infertility treatment in another city?	
No	50%
Yes	50%
Question. What was the number of attempts (treatment) to get pregnant?	
Answer: 0	18%
Answer: 1	32%
Answer: 2	24%
Answer: 3	14%
Answer: 4	6%
Answer: 5	2%
Answer: 9	2%
Answer: 12	2%
Question. What is the cause of infertility?	
Female	50%
Male	14.8%
Mixed factor	18.5%
Infertility without apparent cause	16.7%
Question. Does the couple already have children?	
No	87%
Yes	13%

Despite this, 72.2% of couples consider they have a good quality of life.

Half of the couples (50%) sought treatment in a different city from which they reside. In accordance, 42.6% of the participants reported that access to specialist and medical services was easy only after indication or assistance, and 22.2% considered it difficult to access. Additionally, even though the vast majority of participants (40.7%) rated access to an assisted reproduction clinic and treatment options as easy, 59.3% experienced difficulty or ease only after searching in another city. Even so, more than half of the couples (55.6%) did not think about giving up on treatment due to access difficulties (Table 5).

Regarding perception of medical care, most couples (68.5%) felt welcomed when seeking medical services and treatments, and the rest of the couples were able to express whether they felt helpless or were welcomed after frustrations. Interestingly, only 26% of the couples did not seek more than one medical service, 37% sought care where they were best received and 37% sought care that was financially adequate. An important point about the search for financially adequate treatment is that 83.3% of couples were unaware of free treatment opportunities in other countries.

Furthermore, among the 5 difficulties in accessing medical services and/or treatments, financial issue (high cost of treatments) was the most selected alternative (57.4%). Location (11.1%) and discrimination (1.9%) were also recorded. Exemplifying the financial difficulty, 74.1% of couples recognized an impact on the family budget due to the cost of treatment and 55.6% needed a period between the indication of treatment and the completion of the procedure to raise financial resources. Most (61.1%) of participants did not need to resort to loans or dispose of assets to pay for treatment and 63% did not seek coverage by a health plan or the public health system for assisted reproduction treatment (Table 6).

When asked about their socioeconomic status and family income, the vast majority of couples indicated tranquility, where 81.5% said they had a good socioeconomic situation, 3.7% declared an excellent situation and 14.8% thought their socioeconomic situation was bad. A family income between R$ 3,000 and 5,000 was observed in 53.7% of responders, 31.5% of the couples indicated that they had a family income between R$ 5,000 and R$ 10,000, 7.4% did not fit into the income ranges presented by the questionnaire, 3.7% answered that they had income between R$ 10,000 and R$ 15,000, and 3.7% between R$ 15,000 and R$ 20,000. No participating couple reported having a family income equal to or above R$ 25,000 (Table 7).

Additionally, in order to know the range of the population that seeks treatment for infertility, the questionnaire showed that three out of four couples (75.9%) know friends or have acquaintances who have sought treatment, and several participating couples (37.5%) pointed out that these friends were not able to access infertility treatments.

Table 5 Impact of infertility and difficulty accessing treatment

Question. How does infertility impact/impact the couple's life?	
Strengthened the relationship	38.9%
Weakened the relationship	18.5%
No positively or negatively impact	42.6%
Question. Did infertility and the search for treatment cause moments of anxiety/stress in the couple's life?	
No	16.7%
Yes, only after some treatment attempts	31.5%
Yes	51.9%
Question. The couple considers their quality of life:	
Good	72.2%
Excellent	22.2%
Bad	5.6%
Question. Access to specialist and medical services to treat infertility was:	
Difficult	22.2%
Easy	35.2%
Easy, only after indication/help	42.6%
Question. Access to the assisted reproduction clinic and infertility treatment options was:	
Difficult	20.4%
Easy	40.7%
Easy, after searching in another city/state	38.9%
Question. Has the couple ever thought about giving up on infertility treatment due to some access difficulty?	
No	55.6%
Yes	44.4%

Correlation analysis showed that 95.7% of patients who sought assistance at another city than where they live had already attempted at least one treatment cycle, while only 68% of patients who sought treatment where they lived had already attempted at least one treatment cycle ($p=0.024$).

It is important to note that, in accordance with results presented above, 61.5% of couples who sought treatment in another city/state found it easy to access the assisted reproduction clinic and treatment options only after seeking treatment in a different city from which they reside. Also, 57.7% of couples that did not seek treatment in another city, considered they had easy access ($p=0.003$).

The questionnaire also reported that 42.3% of couples who did not seek treatment in another city sought more than one medical service to treat infertility. Furthermore, 46.2% of couples who sought treatment in another city were looking for a more receptive environment ($p=0.032$). 73.1% of couples who responded they had not sought treatment in another city and 92.3% who had reported they were not aware of free treatment in other countries. However, expectedly, 26.9% of couples who did not find treatment in another location admitted to having knowledge about the gratuitousness in other countries ($p=0.048$).

Finally, it was possible, by this questionnaire, to obtain information about the main difficulties in accessing medical care to treat infertility, where 80.8% of couples who did not seek treatment in another city pointed out that the high cost is the greatest adversity for carrying out the treatment. In accordance, 30.8% of respondents who selected to have sought treatment in another city also found the financial issue as the main limiting factor. Furthermore, it was shown that 23.1% of the couples in the same group indicated the location, that is, living in a city with few resources, as the greatest difficulty encountered by the couple to achieve treatment ($p=0.003$).

Discussion

Infertility is a worldwide public health problem [9], but access to care is heterogeneous, which makes it necessary to observe populations in a more individualized way in order to obtain perspective on impacts of infertility in men and women under diverse location, financial, and social realities. An instrument was thus developed and validated to address these aspects within a population of infertile couples. It is important to note that the development of the questionnaire took into account validation of the research instrument, so that there is methodological coherence and consistency of results [12, 13].

Table 6 Difficulties in accessing medical services and/or treatments

Question. Did the couple feel welcomed in seeking medical services and/or treatment for infertility?	
No	9.3%
Yes	68.5%
Yes, after some frustrations	22.2%
Question. Did the couple seek more than one medical service to treat infertility?	
No, as it does not know other possibilities	13%
No, because there are not many options in your location	13%
Yes, search for adequate service financially	37%
Yes, search for the best welcome service	37%
Question. Has the couple sought or is aware of free treatment in other countries?	
No, no knowledge	83.3%
Yes, has knowledge, but has not obtained access to the other country	1.9%
Yes, has knowledge, but has not tried treatment	14.8%
Question. Point out the greatest difficulty encountered by the couple to access medical services and/or treatment for infertility:	
Discrimination	1.9%
Financial	57.4%
Location	11.1%
Location + financial	14.8%
Didn't find difficulty access	9.3%
Other	5.6%
Question. Has the cost of treatment impacted the family budget?	
No	25.9%
Yes	74.1%
Question. Was there a need to take out loans, have assets or a similar situation to pay for infertility treatment?	
No	61.1%
Yes	38.9%
Question. Was there a need to wait between the diagnosis, the indication of treatment and the performance of the procedure to obtain financial resources?	
No	44.4%
Yes	55.6%
Question. Did the couple seek coverage from health care providers ir the public health system for treatment of infertility?	
No	63%
Yes, but they did not find any	37%

Table 7 Socioeconomic status and family income

Question. The couple considers their socioeconomic status:	
Good	81.5%
Excellent	3.7%
Bad	14.8%
Question. What is the gross family income?	
R$ 3.000 A R$ 5.000	53.7%
R$ 5.000 A R$ 10.000	31.5%
R$ 10.000 A R$ 15.000	3.7%
R$ 15.000 A R$ 20.000	3.7%
R$ 25.000 OR MORE	0%
None of the alternatives	7.4%

The questionnaire developed sought to identify the socioeconomic positions of several patients with infertility who sought medical assistance in São Paulo and Minas Gerais (Brazil), and to identify difficulties in access to reproductive care experienced by the target population, in order to better understand the limits of access to reproductive care and, with that, plan and develop mechanisms to exercise the right to reproductive health and family planning. In this validation study, we observed that the questionnaire was simple to administer, and feedback from patients showed that it was easy to understand, with no need for adjustments. In addition, results demonstrated internal consistency, so that the questionnaire is a valid instrument and allows obtaining information that is statistically possible to be analyzed.

Results analysis allowed us to characterize the main characteristics of participants, indicating age, duration

of infertility, level of education, and color or race. Furthermore, it made it possible to understand the patients' anxiety with the open answers regarding number of treatment attempts, where some couples indicated that they no longer keep track of the count, and referring to the biggest difficulty encountered by the couple to access medical services and/or treatment, where couples were able to express their particular difficulty. Additionally, the last two items of the questionnaire showed how there is a still unknown infertile population.

Corroborating with several authors [5] and as an important factor in discussions aimed at reproductive health rights, the main barriers to reaching treatment were cost of treatment, followed by concentration of clinics in larger cities. Financial sensibility was also an important deciding factor, and a driving force in leading couples to seek treatment alternatives. In addition, the questionnaire exposed how couples assess their quality of life, focusing on the socioeconomic status and possible stress and anxiety in the couple's life. Finally, correlation analysis brought data that support the information acquired, managing to exemplify the main difficulties in accessing treatments to treat infertility and the search for its scope.

In conclusion, the questionnaire proved to be feasible in collecting appropriate information to characterize a target population; that is, the questionnaire was able to meet the main purpose of the study, and the only limitation found was that there was no evaluation by academic judges prior to the pilot test. Even so, the questionnaire proved to be easy for couples in the survey to understand.

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Author contributions
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The authors declare no competing interests.

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ANEXO 4

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RESEARCH Open Access

The search for the principle of justice for infertile couples: characterization of the brazilian population and bioethical discussion

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Abstract

Background Infertility is an increasingly prevalent disease in society and is considered by the World Health Organization to be a public health problem. An important ethical issue arises from the clarification of reproductive rights in a fair and equal way. The objective of this study was to deepen and update the knowledge and discussion about the difficulty of accessing infertility treatments in Brazil.

Methods A cross-sectional observational study was carried out through the application of an online questionnaire that collected the socioeconomic characteristics of couples and identify how barriers to infertility care affect the most vulnerable populations. We included couples who sought medical assistance to achieve pregnancy at two clinics in the states of São Paulo and Minas Gerais.

Results A total of 201 questionnaires were analyzed. Most couples self-declared as white and the average age of wives was 36 years and husbands 38 years. 65% (65%) of couples would proceed with the treatment in a different city to which they lived, 37% evaluated as having easy access to a medical specialist only after indication, and more than half of the participating have thought about giving up the treatment due to some difficulty in accessing it. 39% of participants sought more than one medical service to find better reception, 42% of couples sought more than one medical service to define where it would be better financially, and 67.2% referred to the high cost of treatments, that is, financial issues, as a great difficulty in accessing medical services and/or treatment. Although 72.6% of couples considered having a good quality of life, 54.2% admitted that infertility and the search for treatment generated anxiety/stress in the couple's life.

Conclusion There is a need for public education on reproductive health and for policymakers to raise awareness of the importance of the difficulty that many couples face in seeking treatment to become pregnant, especially in countries with less financial resources. Indeed, it is commonly accepted that there is a universal human right to access healthcare of appropriate quality as a matter of justice. Discussion of access to reproductive technologies should be considered taking into account the longstanding ethical debate regarding fertility, fecundity, and infertility, as well as reproductive care.

Keywords Assisted reproduction treatment, Bioethics, Infertility, Justice, Principle of justice

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Background

Infertility, defined as the inability of a couple to conceive after one year of regular sexual intercourse and without the use of contraceptive methods [1], can occur due to several factors such as alterations to the male or female reproductive tract or its endocrine control, patient age, and metabolic diseases, among other causes. Infertility directly affects the physical and psychological well-being of patients [2]. It is also noteworthy that infertility has become a significant public health and political problem in the last 25 years [3].

For Mascarenhas et al. (2012), estimates of the worldwide prevalence of infertility indicate that approximately 70 million couples will require medical assistance to achieve pregnancy [4]. Several studies show that infertility is an increasingly prevalent disease in society and, therefore, there is a movement to offer treatment to everyone [5, 6]. Although it is still currently necessary to discuss and reinforce reproductive rights, in 1994, during the historic International Conference on Population and Development (ICPD), held in Cairo, the prevention and treatment of infertility were recognized as basic components of rights and care to sexual and reproductive health [7, 8].

Furthermore, in 2001, the World Health Organization (WHO) organized a meeting entitled "Medical, ethical and social aspects of assisted reproduction". At that meeting, in addition to the WHO recommending that infertility be considered a global public health problem, it also recognized it as a disease [9], with a recommendation that infertility management be added to national health education services. It was also recognized that there is a need for affordable assisted reproduction treatments in countries with few resources, using simplified protocols [5].

It is important to admit that infertility and its treatments are the focus of ethical questions about the implications of its use and its accessibility, involving individual, social, political, legal, economic, religious, and gender issues, thus bringing important debates within the scope of bioethics. In other words, a very important ethical issue is envisaged: the clarification of reproductive rights in a fair and egalitarian way [10]. Therefore, while on one hand it is the responsibility of the State, as a representation of society, to provide and promote health and the well-being of the population, on the other there are many ethical discussions regarding what are the limits of this responsibility, especially considering the financial burden of treatments (both to individuals and to the State), limited resources that lead to election of priorities, novel familiar organizations, and even quality of life of the children and families in vulnerable populations [11].

The inequality gap between having or not having access has been increasing yearly. Studies show that, in the United States, for example, most patients who treat infertility through assisted reproduction protocols are white, have a high educational level and high financial income, and also have access to special health insurance, which includes this benefit. In an analysis of family growth research, it was found that women with infertility who did not have access to evaluation and treatment were the ones with the lowest family income and level of education and without health insurance [12].

It is relevant to point out that, in Brazil, the right to family planning is provided for in the Federal Constitution of 1988 [13], however, a large part of the population remains without access to assisted human reproduction services. Low-income persons with infertility face difficulties in seeking free care or are unable to have this right. Another important factor, according to Martins et al. (2019) is that, in addition to the difficulty of access, many couples are unable to solve the problem of infertility due to the lack of information, with negative consequences in the family and social environment [2].

According to Inhorn and Patrizio (2015), only 51% of patients with infertility, in countries with few resources, seek medical care, precisely because the service is expensive, and difficult to access, without the possibility of absence from work and travel costs [14]. In recent years there has been an increase in the number of human reproduction clinics around the world, but they are still concentrated in large centers and are accessible to higher-income couples, as mentioned by the European Society of Human Reproduction and Embryology (ESHRE) task force, they are islands of high-tech assisted reproductive treatment in a sea of poverty and medical malpractice [15, 16]. Few couples have equitable and fair access to these services. The financial costs reflect catastrophically on the family budget (exceeding 40% of the family budget) threatening family survival. In this context, they resort to personal loans, take on more work positions, limit themselves to buying food and clothes, and exhaust their savings [14].

In addition to facing difficulties in achieving fatherhood and/or motherhood, the psychosocial consequences of infertility in high-income countries lead to depression, anxiety, loss of self-esteem, relationship difficulties, lower quality of life, and isolation. In low-income countries, especially in some religious beliefs, having children is a family commitment and there is a stigmatization of women, often considered "at fault" for infertility, leading to domestic and psychological violence, marriage dissolution, fear of the husband separating for another wife, disinheritance, and social isolation. This can result in physical and psychological abuse, polygamy, and even suicide [17].

The principle of justice guarantees, or should guarantee, access in an equitable way and can be translated as

the equitable, fair, and universal distribution of health-related benefits. In Brazil, the practical application of this principle must allow access to all people, to the use of assisted reproduction techniques, because, health is everyone individual's right in addition to being a duty of the State [13]. Thus, on ethical issues, two important points stand out: barriers to access to reproductive care and infertility as a global public health problem [18].

Finally, scientific advances in the medical field and new technologies of assisted human reproduction provide many infertile couples with the realization of the dream of family formation, but there is an increasing incidence of infertility, especially in developing countries, and even more observed where there is socioeconomic inequality, excluding treatment [19]. Thus, the present study aims to address the difficulty of infertile couples to access infertility treatments in developing countries, focusing on the essence of the principle of justice.

Objectives

The present study aimed to deepen and update the knowledge and discussion on the difficulty of accessing infertility treatments in developing countries, focusing on the principle of justice.

The following specific objectives were determined:

- Identify the socioeconomic characteristics of couples with infertility assisted in the states of São Paulo and Minas Gerais - Brazil;
- Identify how barriers to infertility care affect the most vulnerable populations.

Methods

A cross-sectional, multicenter observational study carried out through a bibliographic survey and application of an online questionnaire (Google Forms), developed for the purpose of this study, to couples who sought medical aid to achieve pregnancy at the Oppenheimer Clinic in Santa Rita do Sapucaí (MG) and the Clinic of Fertility and Human Reproduction Gera (SP) between September 2021 and January 2022. An English translation is provided as supplementary material to this manuscript (supplementary file 1). This study was approved by the Research Ethics Committee (CEP) of the Itajubá School of Medicine (CAAE: 50434521.6.0000.5559). The study consisted of 211 couples, who responded appropriately to the questionnaire. All included participants signed an informed consent form agreeing to participate in the study, and Brazilian National Research Ethics Council guidelines were followed.

The questionnaire was applied to couples over 18 years of age and participants who did not correctly fill out the questionnaire were excluded. Because the study focused on access to care for couples who had been actively trying to conceive without medical assistance previously, homosexual couples and single women were also excluded from this analysis.

Data collection

The bibliographic survey was carried out in PubMed, Google Scholar, LILACS, Web of Science, and SciELO databases and legal decrees. For the research, a narrative review of literature was carried out including all articles containing the keywords: infertility, bioethics, ethics based on principles, justice, and assisted reproduction treatment published in English from 1998 to the present date.

Preparation and validation of the questionnaire

The two following stages after the literature review were questionnaire elaboration and pilot study validation, as described below.

Elaboration of the questionnaire

The production of the questionnaire items was carried out by researchers in the area of human reproduction and bioethics. Thirty questions were prepared, 24 of which were nominal (yes/no) and 06 were open-ended, with the aim of absorbing knowledge about personal, cultural, economic, and social identity, in addition to identifying the main difficulties of participants in accessing reproductive care. The questions were organized according to the subjects: (a) sociodemographic characteristics of the couple, seeking to know the age, color/race, and level of education of the participants; (b) time of infertility, attempts to become pregnant and cause of infertility; (c) impact of infertility on the couple's life, that is, whether the couple's relationship was strengthened or weakened due to infertility and if they are going through or have gone through moments of anxiety and stress, in addition to pointing out the perception of quality of life; (d) experiences of seeking care and treatment for infertility, identifying the city where the couples underwent or will undergo the treatment and the difficulties in accessing the necessary treatment, and finally (e) social and economic conditions.

The questionnaire was validated through the elaboration of a scientific article already submitted for publication.

Pilot study

For the pilot study, the online questionnaire was applied to 15 couples over 18 years of age who sought medical treatment for marital infertility and agreed to participate in the study. It was possible to observe whether the participants found it difficult or not to answer the questionnaire and, after statistical analysis, whether the information obtained was satisfactory.

Questionnaire application

After validation in the pilot study, the questionnaire was applied to 211 consecutive couples attending the Oppenheimer clinic between September and December of 2021.

Statistical analysis

For statistical analysis, SPSS 18.0 software for Windows was used. Initially, a descriptive analysis of the data was performed. For continuous numerical variables, mean, standard deviation and 95% confidence interval (95% CI) of the means were presented. For discrete numerical variables, median, interquartile range, minimum and maximum were presented. For frequencies, the percentage and its 95% CI were calculated. Correlation between the variables was verified using Pearson's correlation test (between two continuous numerical variables) or Spearman's correlation test (all other cases). An alpha of 5% was adopted.

Results

The questionnaire was answered by 211 couples who sought medical assistance to achieve pregnancy (104 couples from the Oppenheimer Clinic in Santa Rita do Sapucaí – MG and 107 couples from the Clinic of Fertility and Human Reproduction Gera – SP). As they were not considered cases of infertility, homosexual couples (6 questionnaires) and couples where the partner indicated having had a vasectomy (4 questionnaires) were excluded. In this way, a total of 201 questionnaires were analyzed and the results are presented according to the subjects indicated above.

Table 1 Individual characteristics of respondents to the questionnaire

Variable	Value
Wife age (years)	
Mean (Standard Deviation)	36.7 (5.30)
95% CI	[35.9; 37.4]
Min – Max	20–50
Husband age (years)	
Mean (Standard Deviation)	38.6 (6.96)
95% CI	[37.7; 39.6]
Min – Max	20–63
Infertility (years)	
Mean (Standard Deviation)	6.0 (4.29)
95% CI	[5.4; 6.6]
Min – Max	0.5–25
Number of treatments (attempts)	
Mean (Standard Deviation)	2.0 (2.05)
95% CI	[1.7; 2.2]
Min – Max	0–12

Sociodemographic characteristics of the couple, time of infertility, attempts to become pregnant, and level of education

Starting with the analysis of the age of the partners, it was identified that the average age of the wives was 36.7 years and the average age of the husbands was 38.6 years, observing couples that were still young. The duration of infertility ranged from 6 months to 25 years, with a mean time of 6 years.

Regarding the number of treatments performed to get pregnant, the analysis showed that most couples were making the first or second attempt (Table 1), however, it is important to report that 5.47% of couples showed a lot of distress in the questionnaire when answering that they no longer knew, because they are various, the exact number of attempts.

The questionnaire exposed the level of education for both partners of the couple. It was observed that, among the wives (first partner), 19% indicated that they had attended high school, 32% had completed higher education and 38% had postgraduate degrees. Among the husbands (second partner), 36% had an education up to high school, 27% had completed higher education and 20% had a graduate degree.

When analyzing the answers referring to color or race, it was found that most participants (69.2% - wives and 72.6% - husbands) declared themselves white, followed by brown (22% - wives and 20.4% % - husbands) and black (6.5% - wives and 5.5% husbands). Asian races (1.5% - wives and 1.0% - husbands) and indigenous races (1.0% - wives and 0.5% - husbands) were the least indicated options.

In order to characterize the couples, the questionnaire sought to understand whether the participants already had children and whether they knew the cause of infertility. Only 18% of couples already had a previous conception. And, it was shown that in 47.3% of couples, the cause of infertility is female, in 16.4% the cause is male, in 18.4% the cause is considered mixed and in 18% the infertility is without apparent cause.

Experiences of seeking care and treatment for infertility and difficulties in accessing treatment

Interestingly, when asked about the city in which they lived and the city where they would undergo the treatment to achieve pregnancy, 65% of the participants indicated that they would proceed with the treatment in a different city in which they lived, indicating how Brazilian couples search for treatment. Following this reasoning, it was observed that 34.3% of the couples considered having easy access to an assisted reproduction clinic and to infertility treatment options only after searching in a different city in which they lived, and, still, 21.4% indicated difficult access.

The questionnaire showed that 39% of couples considered it easy to access a specialist and medical services to treat infertility, 37% rated it easy to access only after an indication or help, and 24.4% found it difficult to access a specialist doctor. It is important to highlight that more than half of the participating couples (51.7%) have already thought about giving up on treatment due to some difficulty in accessing them.

Although there are adversities, 61.2% of couples felt welcomed in the search for medical services and treatment for infertility, but it still cannot be overlooked that 28% of couples felt welcomed after some frustrating experiences, and 11% were not welcomed. To understand what couples prioritize when choosing a specialized medical service, we asked whether the couple sought more than one service and what motivated them. The answers showed that 39% of the participants sought more than one medical service until they found better care, 42% of the couples sought more than one medical service until they defined where it would be better financially, 14% answered that they did not seek more than one medical service due to lack of services in their location and only 5.5% did not seek more than one service due to lack of knowledge. Information was also obtained that 77.6% of couples are not aware of free treatment in other countries.

As already indicated in the previous items of the questionnaire, 67.2% of couples demonstrated the high cost of treatments, that is, financial issues, as the greatest difficulty in accessing medical services and/or treatment and 13% of couples pointed to both financial and location difficulties as factors that made access difficult. In this group of participants, only 0.5% of couples think that the greatest difficulty in access involves discrimination.

Impact of infertility on the couple's life and perception of quality of life

Some items of the questionnaire addressed quality of life and personal sentiments experienced by couples. Regarding the impact of infertility on the couple's life, 40% said that the relationship was strengthened by suffering infertility, 21.4% of the couples indicated that the relationship was weakened and 39% did not feel a positive or negative impact on the relationship. Then, 54.2% of couples admitted that infertility and the search for treatment generated anxiety/stress in the couple's life from the beginning, and 33% indicated these feelings only after some treatment attempts. However, despite the moments of anxiety and stress, 24.4% of the participants consider having a great quality of life, 72.6% consider having a good quality of life and only 3.0% of couples consider having a bad quality of life.

Social and economic conditions

We also sought to deepen our knowledge of the socioeconomic status and family income of the participating couples. For 78.1% of couples, the cost of treatment impacted the family budget and 48.3% of couples had to resort to loans or have assets to be able to afford treatment. In addition, 65.2% of the couples found it necessary, after diagnosis and treatment, to wait to obtain financial resources to perform the procedure and 45.3% sought coverage by health plans or the public health system, but they remained helpless.

It was observed that most participating couples have a family income of up to 10,000 reais (1 real – 0,18 €). The option of income between 3,000 and 5,000 was selected by 45% of couples, 31.3% of participants indicated income between 5,000 and 10,000, 8.5% of couples said they had a family income between 10,000 and 15,000, 6.5% of couples have an income between 15,000 and 20,000, only 2% of couples reported having an income of 25,000 or more, and 7% of couples selected an income range not indicated in the options offered, suggesting a family income below 3,000 reais.

Additionally, couples with a higher income range had better overall self-assessed quality of life ($p=0.010$). Furthermore, it was noted that having better financial conditions is associated with easier access to the assisted reproduction clinic and treatments ($p<0.0001$) and these couples think less about giving up on treatment due to some difficulty in accessing them. ($p=0.021$).

It is important to note that the questionnaire left free space for the participating couples to feel free to enter comments. Most of the comments (34.72%) were to indicate the immense financial difficulty to access and carry out the treatments suggested by the medical service. Additionally, couples put into words their anxiety about achieving the dream of motherhood/fatherhood and how distressing the whole process can be. For example, some comments indicate: anxiety was an impacting factor among treatment attempts; infertility generates feelings of anguish and frustration; the way is long and painful; the treatment generates many frustrated expectations; my dream is to be a mother, but the treatment is distressing.

Finally, the questionnaire presented the information that several participating couples (71.1%) have friends or acquaintances who also seek treatment to achieve pregnancy and that 27.4% of these friends or acquaintances managed to access treatment with difficulty, and that 11% are still helpless, that is, they have not yet been able to access treatment.

Discussion

Infertility, according to the WHO, is a public health problem and affects about 186 million people worldwide. In Brazil, an estimated 8 million individuals may bear this condition [20, 21]. As a treatment, assisted reproduction techniques allow millions of couples who experience infertility the possibility of becoming pregnant, especially in low- and middle-income countries, where we find a higher incidence of infertility [4–6, 22].

The results observed in this study allowed us to understand that the narrative of couples who seek pregnancy through assisted reproduction techniques presents important reflections on the experience of undergoing infertility and, also, reflections on the relationship between the difficulties access to treatments and the socioeconomic characteristics of these couples. The reality of working as an infertility specialist in Brazil, working in the Minas Gerais state countryside, is in line with the responses of the participating couples: a large number of anguished patients are received without a correct investigation of the reason for infertility, and many couples never considered they would be able to commute to larger cities, due to their socioeconomic and cultural level, to carry out this investigation with a specialist. Unfortunately, a limitation was observed in the study by applying a questionnaire because there was no evaluation by a committee of experts before the pilot test.

Indeed, in most countries access to healthcare of appropriate quality is considered a basic and fundamental human right, even a universal human right [23]. It follows that all societies, more or less developed, should promote an intensive debate on the establishment of priorities in healthcare so that it is socially determined, in accordance with the principle of public accountability, if infertility treatments should be offered in the basic healthcare package delivered to all citizens [24]. This is particularly challenging given the many financial burdens already imposed by increased cost of healthcare (both in developed and in developing nations), as well as novel constitutions of familial relations that render infertility treatment necessary for patients that would not fall under the classic definition of infertility (i.e. after one year of unprotected sexual relations) [11]. Even in countries where infertility treatment is gratuitously offered to infertile patients, there are barriers imposed, such as female age, number of previous children, or number of attempts [25]. It is of utmost importance, then, that such discussions are carried out involving lawmakers, health providers, stakeholders in the access-to-care pipeline and, especially, patients themselves – especially considering that medical treatment and assisted reproduction are quite often not the only options for managing infertility [25].

After overcoming the access barriers, at first, with adequate care and a confirmed diagnosis, the couples demonstrate satisfaction and are extremely happy, believing that the infertility problem can be solved and, thus, the anguish and anxiety will end. However, from the moment of indication of in vitro fertilization, the costs of the in vitro fertilization treatment (since it is in the private sector), and the need to perform it in another center, a large percentage gives up on having the procedure performed, while other couples responded to be still trying to find financial means for treatment. Only a fraction with higher socioeconomic conditions declared to be able to carry out the treatment immediately.

Corroborating a study by Alon et al. (2021), it was observed that access to assisted reproduction techniques has a cultural inequality, where couples with more schooling (university and graduate studies) were those who managed to resort to specialized services, with 70% of the wives and 47% of the husbands having a higher level of education [26]. A survey by Iba et al. (2021) demonstrated that there is an association between schooling and the search for medical help, exemplifying that people with higher education exhibit more behavior of seeking medical help; in addition, couples with better financial, psychological, social and cultural conditions also present greater search for treatment. Therefore, this group has an awareness of infertility problems, leading to coping with the problem and seeking treatment [27].

Another important finding of the results of the current study is that a large percentage of the wives have a high level of education. Chambers et al. (2013) emphasize that the high level of schooling of wives occurs by postponing pregnancy by concentrating on the profession, and this leads to differences in the pattern of infertility and procreation due to greater purchasing power and facilities in performing in vitro fertilization [28].

As observed, a large percentage of the patients who answered the questionnaire identified themselves as white, showing the racial disparity in access to assisted reproduction treatments [29, 30]. According to Butts (2021), black patients begin the search for infertility research 6 to 15 months after white patients do, and they still take a longer time to perform adequate treatment, which negatively reflects on ovarian reserve, leading them to undergo more cycles of treatment with greater costs and lesser successes, characterizing racial inequalities and the absence of equal access to treatments [31].

The result of the study also showed that all care for couples who seek to solve infertility problems in Brazil is carried out in private clinics, directing the treatment to only a portion of the population with greater purchasing power, excluding or creating difficulties for less economically favored couples. The main barrier to accessing treatments suggested by the medical service, according to

the study, is financial. Hammarberg and Kirkman (2013) agree and state that the search for financial resources impacts the family budget and possessions, with loans or withdrawal of treatment [16], highlighting the need to make assisted reproduction treatments more accessible through public offerings or supplementary health plans, in pursuit of the principle of justice [32, 33].

Another point, demonstrated in the study and also impacting treatment withdrawal, is the difficulty of accessing specialists in the region where they live, limiting specialists and clinics to large centers and many take years for specialized care. This disparity in access to infertility care due to socioeconomic conditions, ethnicity, and the geographic area does not guarantee equity, and promoting health is guaranteeing rights and intervening in inequalities in the distribution of goods and services [34, 35].

Additionally, infertility is known to cause psychological and social distress such as fear, guilt, depression, marital stress, emotional abuse, intimate partner violence, divorce and partner abandonment, social isolation, economic deprivation, loss of social status, and in some regions (e.g., Africa and Asia), even famine, disease, violence-induced suicide, and loss of dignity in death [16, 17, 36]. To identify this impact on patients' lives, the questionnaire also addressed questions about the perception of the quality of life of infertile couples, identifying moments of anxiety, anguish, and stress due to infertility and the search for treatment. It was noted that couples manage to maintain hope, but emphasize moments of suffering and pain. In addition to showing stress throughout the process, from getting access to a specialist to completing the treatment, the couples stated that the path to realizing their dream of motherhood/fatherhood was very distressing.

After characterizing the barriers and pointing out the disparities in access to infertility treatments, it became possible to deepen the bioethical argument, in particular, the principle of justice. Questions arise regarding the health of the population and the health system, including its structure, financing, and management of its resources in relation to public policies [37]. In Brazil, the 1988 Constitution establishes health as a social right, but in the current scenario and in the political culture of government practices, the State lacks commitment to universal access to this right [22, 33]. Due to this, intervention bioethics seeks to demonstrate the importance of investments and government actions that prioritize healthcare for the less favored classes [32]. Bioethics can contribute to the search for improvements in health and justice conditions [38, 39], and this search must be broad, that is, involve social conditions, discrimination, difficulty in accessing information, and to the treatments proposed by the healthcare system.

Thus, according to some researchers, there are three ethical principles that provide an ethical basis for assisted reproduction treatments: the principle of freedom, the principle of utility, and the principle of justice [10, 40], which refers to equal treatment and fair distribution of State funds for health, research, and prevention. However, medical ethics is based on society's moral, religious, and philosophical ideas and principles and is influenced by economics, policies, and laws [41]. This creates tension between the principles of justice and utility, which can result in a disparity in the availability and access to assisted reproductive technology services between the rich and poor [42, 43].

It is pertinent to suggest that actions should be implemented to achieve reproductive justice around the world and especially in countries with fewer financial resources. This includes promoting educational programs to prevent infertility before it sets in, early detection of diseases linked to infertility, such as sexually transmitted infections and post-abortion consequences, and reversing global obesity, smoking, and alcohol with its reflection on the hormonal axis of patients [16]. Furthermore, a greater ethical and sociocultural awareness of infertility and the impact of childlessness is warranted, where fatherhood and motherhood are socially obligatory, seeking to support these patients who live in marginality and ostracism, proposing new paths such as adoption or even support for not having children, deconstructing old concepts. Finally, it is of especial importance to simplify diagnostic procedures and infertility treatment, bringing lower cost protocols for ovarian stimulation and IVF procedure, being available and within reach of a larger part of the population. A potential solution is to promote actions that have a public-private partnership with political and governmental support [16].

The Brazilian law 11.935/2009 of mandatory coverage regarding family planning does not state the types of treatment that should be covered. Thus, it is understood that the exclusion of coverage for treatments involving infertility is subject to legal questioning. There was a modification of this law from its original wording in Art. 35-C, by including in the list of mandatory coverage of health plan procedures related to family planning [44]. Even in the face of some judicialization, the judiciary has been more favorable to the derogation of item III of Art. 10 of the Health Insurance Law. Therefore, it is necessary to prioritize public health initiatives to prevent infertility, interventions to reduce costs, and provide specific treatments [5, 18].

Affordable infertility treatment can only be successfully introduced in developing countries if sociocultural and economic prerequisites are met and governments can be persuaded to support its introduction. Establishing contacts with the authorities and discussing infertility

in public health structures is fundamental [12, 36, 37]. It also raises the question of contributions from the pharmaceutical and medical industry, with cheaper equipment, lower cost medication, the manufacture of basic products and laboratories with lower costs, and simplification of procedures so that are accessible, of good quality, and of low economic cost [12, 17].

Global access to infertility care in developing countries can only be achieved when it is linked to family planning programs, and national and international health strategies. This would entail a shift in the conventional view, which has focused on reducing total fertility rates, to also focus on infertility in patients at need. This would thus emphasize that infertility prevention measures, especially in developing and low-income countries, are essential and must be effective and reach the most vulnerable populations. It is suggested that, in Brazil, these measures are part of a government program within the Sistema Único de Saúde - SUS (Health Single System) [21, 36, 45].

Finally, since infertility is a disease and is considered by the WHO as a public health problem, ways must be sought for its prevention and treatment, seeking egalitarian health. Therefore, the principles of bioethics are fundamental and should guide the dilemmas faced. The principle of justice establishes a fundamental condition of equity and impartiality, and everyone must be treated ethically and given what is due to them.

Conclusions

Infertility is considered by WHO to be a public health problem with psychological and social repercussions. Its incidence has increased, mainly in regions and countries with less favored socioeconomic and cultural conditions, precisely where access to treatment resources is non-existent. The main barrier to accessing treatment is financial, as the costs are high and have a negative impact on the family budget or even make it impossible to do so. Also, treatments are performed only in private clinics in large centers and patients are forced to move to these regions or give up treatment.

In this study, we tried to find out the conditions of access to infertility treatments in a justice and equity approach. Methodologically this study enrolled only heterosexual couples with clinical diagnosis of infertility. Single women or homosexual couples were excluded because access to reproductive technologies in those cases has a different ethical context. Nevertheless, future studies should also approach this issue. Bioethics, in its critical and interventional role, with a focus on protecting the more fragile members of society, should contribute in the discussion and consolidation of reproductive justice.

The pandemic limited the study because many patients abandoned or postponed treatment during this period. Other studies must be carried out, given the relevance of the theme and the negative impact of experiencing infertility, in order to seek means of justice in the equal treatment of patients.

Supplementary Information

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Supplementary Material 1

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Authors' contributions

DO – conception of the study, data collection, results interpretation, drafting of the manuscript. Final approval for submission. FR – conception of the study, results interpretation, correction of the manuscript. Final approval for submission. RN – conception of the study, results interpretation, correction of the manuscript. Final approval for submission.

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Data Availability

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

Institutional Review Board approval was received from the Research Ethics Committee of the Itajubá School of Medicine (CAAE: 50434521.6.0000.5559). All included participants signed an informed consent form agreeing to participate in the study, and Brazilian National Research Ethics Council guidelines were followed.

Consent for publication

Not applicable.

Competing Interests

The authors declare that they have no competing interests.

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ANEXO 5

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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, which leads to a movement that seeks equality in access to infertility treatments. It is important to identify ethical issues involved and understand how discussions about justice occur in the provision of medical infertility treatment. Therefore, a literature review was carried out using Web of Science, Pubmed, and Google Scholar databases. In general, articles demonstrated that most countries do not meet ethical requirements of distributive justice. Articles demonstrate barriers to access and resistance that exists in accepting infertility as a health problem. They also demonstrated suffering that infertility causes and 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 individuals can improve health and is also related to the feeling of justice on the part of health professionals and policy makers.

Keywords: Bioethics. Infertility. Reproductive rights

Resumo

Bioética nas adversidades para acesso a tratamento de infertilidade

Casais inférteis enfrentam barreiras no acesso a cuidados médicos, o que leva a um movimento que busca a igualdade no acesso aos tratamentos de infertilidade. É importante identificar questões éticas envolvidas e compreender como ocorrem as discussões sobre justiça na prestação de tratamento de infertilidade. Portanto, foi realizada uma revisão de literatura nas bases de dados Web of Science, Pubmed e Google Scholar. Em geral, os artigos demonstraram que a maioria dos países não cumpre os requisitos éticos da justiça distributiva. Os artigos demonstraram barreiras

de acesso e a resistência que existe na aceitação da infertilidade como uma doença. Demonstraram o sofrimento que a infertilidade causa e a urgência em colocar em prática conceitos éticos para que soluções sejam adotadas. Em conclusão, umm debate ético que alcance a provisão de bem-estar para todos pode melhorar a saúde e também está relacionado ao sentimento de justiça por parte dos profissionais de saúde e políticos.
Palavras-chave: Bioética. Infertilidade. Direitos reprodutivos

Resumen

Bioética en las adversidades para el acceso al tratamiento de la infertilidad

Las parejas infértiles enfrentan barreras para acceder a la atención médica, lo que conduce a un movimiento que busca la igualdad de acceso a los tratamientos de infertilidad. Es importante identificar las cuestiones éticas implicadas y comprender cómo se producen los debates sobre la justicia en la prestación de tratamientos para la infertilidad. Por lo tanto, se realizó una revisión de la literatura en las bases de datos Web of Science, Pubmed y Google Scholar. En general, los artículos demostraron que la mayoría de los países no cumplen con los requisitos éticos de la justicia distributiva. Los artículos demostraron las barreras de acceso y la resistencia que existe a la hora de aceptar la infertilidad como una enfermedad. Demostraron el sufrimiento que causa la infertilidad y la urgencia de poner en práctica conceptos éticos para poder adoptar soluciones. En conclusión, un debate ético que logre la provisión de bienestar para todos puede mejorar la salud y también está relacionado con el sentimiento de justicia por parte de los profesionales de la salud y los políticos.
Palabras clave: Bioética. Esterilidad. Derechos reproductivos

Declaram não haver conflito de interesse.

The World Health Organization (WHO), since 2009, assumes infertility as a disease and a global public health problem [1] that can affect approximately 15% of couples of reproductive age [2], generating an unexpected situation of distress and stress [3]. In addition, throughout the world, there are several barriers or impediments that some couples face in order to benefit from specialized medical care and treatments to achieve pregnancy [4], which leads to discussions and mobilizations that seek distributive justice and equal access to medical centers and assisted human reproduction treatments.

In several countries, there is no specific law on the right to infertility treatment, but it is important to note that the concept of reproductive justice is based on four fundamental principles, and one of them is that everyone has the right to have children [5]. An article published by the European Society for Human Reproduction and Embryology (ESHRE) in 2008 reinforces that the right to equal access to basic health care is essential to ensure that people have a range of opportunities for medical care, regardless of their income or financial means [6]. It also informs that the most important factor that causes disparity in access to health care is the individuals' ability to pay [6].

Concomitantly, medical conduct based on ethical principles stands out: respect for autonomy of choice, beneficence, non-maleficence and, especially in the current context, justice [7]. The principle of justice provides the patient with fair and equitable access to available health services [8]. It is also important to emphasize that ethics and biolaw must accompany advances in the area of reproductive medicine to enable humanist conduct and followers of rights. The look of ethics and biolaw recalls that treatment in the health area should override any lucrative purpose and prioritize the good of life [9].

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

However, even observing millions of cases of successful assisted reproduction treatment and admiring the medical and technological evolution of these treatments, it is also noteworthy the impossibility or difficulty of access experienced by many infertile couples, especially in developing countries or poorer regions [11]. In this manner, it appears that despite the existence of recognition, even if still insufficient, for the right to reproductive health and family planning, many couples still witness the lack of opportunity, whether financial, social, communication or location, to carry out treatment for infertility to achieve motherhood and fatherhood.

At the same time, when considering the different circumstances in which a

population lives, a study published in 2017 raises an important point that confirms the need to propose tools to make it feasible to reach quality health services considering the resources available from a specific community, and it is essential to assume the difficulty in providing the right to the same state of health for all, as there are different conjunctures, such as family, social and economic conditions [13].

Finally, promoting the universal right of access to health care is still a challenge and we recognize that it is unfeasible to idealize the right to services to treat infertility for all individuals without observing the particularities of a community and without involving a bioethical content, as the fundamental right to procreate is based on solid moral and ethical concepts[14]. With this, it becomes important to identify the ethical issues involved and to understand how discussions and awareness about the fairness of providing medical care and treatment opportunities for infertility to couples around the world are evolving.

Methods

This study was carried out from April to June 2023 through bibliographical research on the theme “Bioethics in the adversities of access to assisted human reproduction”, using the Web of Science, Pubmed and Google Scholar databases, chapters of books and websites of Organizations and Societies. The keywords used were taken from the Health Sciences Descriptors (DeCS): Bioethics, Infertility, Health disparity, Health inequity, Health rights and Reproductive Health Services. The inclusion criterion was articles published from the year 1980 in English or Portuguese.

Literature review

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

Studies claim that infertility has been increasing its incidence and that developing countries cover most cases [4], reaching 30% infertility rate in some populations [15]. The high prevalence in certain regions may suggest lifestyle, environmental problems that affect fertility of the local population, and/or disparities in

access to medical specialists [16].

When a data survey is carried out to understand how individuals in developed and developing countries have access to infertility treatments, it is identified that most countries do not comply with ethical requirement of distributive justice and do not offer public funding for infertility treatment. However, even in countries, such as the United Kingdom, where medical treatment is funded by the State and available on the National Health Service (NHS) [17], as policy makers consider infertility to be a disease, there are discourses that disagree with this [18] and arguments that see infertility only as a failure pointed out by social and cultural pressure to have children [19]. However, the literature has an abundance of articles attesting that infertility, for many women and men, is not just about the impossibility of having children, but it is a rupture of life project and continuity, causing psychological suffering and a feeling of inability to achieve primary life expectancy [20-22].

The Universal Declaration on Bioethics and Human Rights (2005) proclaims as one of its objectives [23] (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.* Furthermore, Article 16:1 of the Universal Declaration of Human Rights states that *men and women of legal age, without any limitation due to race, ethnicity, nationality or religion, have the right to marry and to found a family* and Article 25 includes the right to medical assistance [24]. Thus, infertility treatment is considered a human rights issue, but often, in practice, its inclusion as mandatory coverage still depends on justifications [25]. Additionally, studies show unequal access to assisted reproduction treatments or even to the first consultation with a fertility specialist for reasons such as (i) location: less developed countries or states, (ii) financial: public health that does not offer more expensive treatments, (iii) racial and ethnic disparities[15,26] and, (iv) lack of disclosure or communication: couples remain ignorant of the health problem and the possibility of treatment. Thus, assisted reproduction treatment is absent or inaccessible for many infertile couples around the world.

A 2021 article points out that attempts to promote equitable access to medical services and infertility treatments are not few, including actions by the United Nations (UN) [24], the WHO and a declaration by the Center for Disease Control (CDC) of the United States (USA) placing the diagnosis and treatment of infertility as a national

public health priority [27]. However, often, treatments for infertility are still interpreted as being elective and the resistance that exists in assuming infertility as a health problem is notorious.

Evidently, due to advances in the area of reproductive medicine that make possible the chances of a couple or an individual to have children, many lines of thought do not cover all the causes of infertility as a disease. Maung demonstrates that this argument is important for a medical, ethical, and philosophical debate, as it indicates that the problem with infertility is that it is a heterogeneous category and that there is disagreement about which types of infertility qualify as a disease [18].

In contrast to resistance, a study by Rutstein and Iqbal demonstrated how most cases of infertility stem from the inability to conceive a healthy baby when analyzing information from 47 demographic and health surveys in developing countries and estimated that, in 2002, more than 186 million married women of reproductive age had primary or secondary infertility [28]. Moreover, in addition to the importance of general well-being for the health of a human being, and well-being can even be associated with the realization of motherhood and/or fatherhood, there are numerous causes that can lead couples to need assisted reproduction treatment; for example, in addition to infertility itself, there are people who resort to assisted reproduction techniques to avoid the birth of a child with a specific genetic disease [6].

There is an effort by organizations and medical professionals 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 stands out, which, based on the definition of reproductive justice, seeks to overcome adversities, and bring low-cost fertilization treatments to regions with limited resources [4]. Even so, it is suggested that public policies should assume infertility as a public health problem and seek financial resources within budgetary allocations or public-private partnerships to alleviate the lack of accessibility. Furthermore, Nunes et al., 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].

Even so, it is perceived that the discussion of offering public funding to treat infertility follows a conservative line and, although it can be rationally understood, the resistant pretexts in providing specialized medical care and treatment financed by the

State or covered by medical agreements and health insurance, when we follow ethical principles, 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 to make a health system with equal access viable implies assuming that it is best to adopt the cost-effectiveness criterion [29] and according to Brown *et al*, the strategy of offering public infertility treatment is clear in that it involves an ethical discussion considering 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 problems and cultural [30].

Thus, it is seen that an important point to offer access to all who need treatment is to accept that infertility is a disease because it also causes changes in well-being. However, the ethical discussion still needs to be expanded, because in addition to admitting that infertility is a disease, deeply understanding what the access barriers are, allows knowing the details and drives the search for alternatives and solutions to provide basic healthcare to all. The ESHRE indicates that even in countries that offer reimbursement for infertility treatment through the public system or with insurance coverage, groups with low income and low education make significantly less use of health services, clarifying the importance of educating the population and having an awareness of fertility care and treatment options[6]. In addition, ensuring equitable access to infertility assessment, treatment, and care is seen to depend on the investment of health professionals and policy makers [27].

The most current data inform that, for example, black women, when compared to white women, have fewer opportunities to be evaluated and treated for infertility, as well as that the population of lower socioeconomic status seeks less infertility services [31]. Ombelet *et al*. points out that even with the implementation of low-cost treatments, it is unlikely to become accessible to everyone, and that for men and women living in extreme poverty, the ideal would be socio-political interventions in favor of improving the economic situation [32]. Despite identifying possible barriers to access, we still face great difficulty in interpreting the causes in a way that brings efficient solutions. Corroborating this thought, Perritt and Eugene state that access inequalities are poorly understood and suggest racism and economic contrast as likely causes [27].

Bahamondes and Makuch (2014) referred to 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, the current study analyzed

through a survey of the literature that infertility affects individuals with different conditions around the world, but much emphasis is placed on the fact that the preventable causes of infertility are different between some groups, and therefore, perhaps different actions are necessary. For example, it is indicated 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], it being understood that preventive public health policies and better assistance to this group would already have a positive effect on the reduction of the incidence of infertility. However, the avoidable cause of infertility and the search for treatment by economically stable people can be justified due to the postponement of motherhood, prioritizing career achievement or financial stability. In many Western countries, women try to conceive their first child after achieving other goals in life, when fertility possibly begins to decline [35]. Additionally, cultural, and environmental factors interfere with fertility and differ between regions and countries [36].

With this, it can be considered that the ethical debate should have the same primary objective in designing distributive justice, but could have different approaches, according to different scenarios, in order to then achieve equity of access. In favor of this premise, White et al. (2006) expose the issue of sociocultural barriers, indicating language obstacles, communication elements, notions of privacy and prejudices about health care [37]. In any case, the magnitude of the suffering that infertility causes in people's lives is observed and, therefore, the urgency of this awareness and of putting ethical concepts into practice so that solutions are adopted by health professionals and politicians. As exposed by Nunes *et al* , it is important to strive for a healthy society, thus being more balanced and productive. To achieve this, there must be efforts on a global scale to implement human rights in an accelerated manner and the right of access to health must be considered a priority, even if it still depends on citizen solidarity to be enjoyed [13].

Final considerations

Arguably, with the review of the literature, it is noted that overcoming the barriers to accessing infertility treatments depends on a comprehensive and continuous ethical approach. In addition to the most exposed difficulties in access, such as financial issues, social issues, racial issues, and location, there are still differences in

considering infertility a disease, on the costs of treatment financed by the State, and the discussion on offering infertility treatment to couples in extreme poverty.

With the analysis herein, it could also be observed that autonomy and justice are the ethical principles most involved in this discussion. This has led, in addition, to enunciate an ethical debate with various points depending on the quality of life conditions, expectations and consequences on people's lives in different parts of the world. It becomes clear that globally, that is, not only in developing countries, but also in developed countries, there is a need to adopt measures for the fulfillment of human rights, prioritizing health care depending on the context of each nation or country location.

Finally, it is concluded that, 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 that towards the offering well-being to all individuals, since offering health is also related to the feeling of justice and welcome on the part of health professionals and policy makers.

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ANEXO 6

ORIGINAL ARTICLE

Quality of life in infertile patients in Brazil: religious spirituality as a coping mechanism.

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Abstract

Background: Due to social pressure and individual desire to have children, infertility is often accompanied by suffering and decreased quality of life. Among possible coping mechanisms, religion has been suggested to help improve quality of life. The objective of this study was to verify, in a cohort of Brazilian women undergoing infertility treatment, if there is a relationship between religiosity and quality of life. **Methods**: The sample consisted of 104 volunteer Brazilian women who sought infertility treatment. A FertiQoL and a Religiosity questionnaire were administered. Descriptive statistics were computed, and groups were compared using a Chi-square test. **Results**: Most of the participating in the study stated that religiosity associates to well-being, and 90% of them concluded that religiosity was an important process during infertility treatment. The study found that religiosity leads to improved adaptive coping capacity. **Conclusions**: Although it is difficult to demonstrate causality, results strongly suggest that religiosity plays an important role in adjusting psychological aspects of infertile women.

Keywords: Female infertility; fertilization clinics; medicine; quality of life; religion.

Background

Infertility, defined as the failure to conceive after one year of regular sexual intercourse without the use of contraceptive measures **(1)**, is considered a global health issue **(2)**. It is estimated that 15% of couples are infertile, and a 50% increase in cases has been observed over the past two decades **(3)**. For the purpose of the current study, it is highlighted that in Brazil, according to data from the Brazilian Institute of Geography and Statistics (IBGE), approximately 15 to 20% of couples of reproductive age have infertility **(4)**.

The desire to bear children and constitute a family is a constituent of human instinct and, under this premise, infertility has a potentially devastating effect for couples, leading to negative emotional effects and impacting various aspects of conjugal life **(5)**. In some cultures, there is still an increased social burden of infertility that may lead to feelings of guilt, loneliness, and social stress **(6,7)**.

Some authors have observed a relation between infertility and conjugal dissatisfaction or distress, with negative effects on conjugal life **(8)**. Moreover, although a male factor is as prevalent as a female factor **(9)**, many still consider infertility mostly

a female issue, especially in developing countries, or in countries where a maternal role is valued over the women themselves **(8,10)**. As a result, women are clearly even more affected by the difficulty in achieving motherhood, living in emotional stress and having a lower quality of life than men **(11-13)**. A recent study found a prevalence of up to 52% of depression symptoms in infertile women **(14)**.

Moreover, the impact of infertility leads many couples to physical, psychological, social, and spiritual distress, leading to questions regarding their existence **(15,16)**. In order to achieve emotional balance, some couples embark on a spiritual journey, seeking new meaning or purpose in life through understanding negative events **(16,17)**. A Koenig review (2012) pointed an association between spirituality/religiosity with quality of life and mental health, demonstrating a positive association with emotions such as hope, optimism and purpose or meaning **(18)**.

Although there is no consensus on the definitions of religiosity and spirituality, Renetzky (1979) designates the spiritual dimension as: (i) the power within the human being, giving meaning, purpose, and fulfillment to life, suffering and death; (ii) the individual's will to live; and (iii) the individual's belief and faith in himself, others, and God. In this way, religious practices and spiritual beliefs are involved by similar feelings **(19)** and, the context of this study, sought to analyze how much spirituality in connection with religion and the strengthening of the bond with faith reflects on the quality of life of the participants.

Studies have shown that belief in a divine being or in eternal life may lead to increased resilience; likewise, infertile couples have been shown to seek counseling from religious leaders more often than with psychologists or support groups **(17,20)**. It is also noteworthy that patients that have incorporated prayers in their infertility treatment routines have obtained increased success rates, and that religion is a good coping strategy for patients with traumatic and adverse situations **(21,22)**. The importance of treating the infertile couple in a way that embraces all their needs is already indicated by the European Society of Human Reproduction and Embryology (ESHRE) and it recommends routine psychosocial care to reduce stress and restore patients' well-being and adherence to infertility treatments **(23)**.

Finally, diagnosis of infertility is often difficult, both physically and mentally, and different coping mechanisms are often experienced throughout treatment. We hypothesize that religious belief and practice may be an important part of coping mechanisms in women undergoing infertility treatment in Brazil. Therefore, in this study

we set out to assess, in a cohort of Brazilian women undergoing infertility workup and treatment for conjugal infertility, if religion is related to quality of life.

Methods

A cross-sectional study was carried out at the Assisted Reproduction Clinic – Gera Clinic – São Paulo unit. A total of 104 women were included, aged between 18 and 50 years old. Inclusion criteria were age (between 18 and 50 years old) and a diagnosis of conjugal infertility. Institutional review board approval was received from the Itajubá School of Medicine (project number 3.846.249). Resolution 196/96 guidelines from the Brazilian National Health Council were followed.

Data were collected throughout 2020, via a Google Forms questionnaire, sent by email, and included an informed consent where the patient agreed to participate in the study. For data collection, the following questionnaires were applied:

- FertiQoL (Fertility Quality of Life): An instrument translated and revised into Portuguese, consisting of twenty-six items, developed, and validated by Boivin et al. (2011) **(24)** that allows evaluation of quality of life of men and women who experience fertility problems. Administration time was approximately 10 to 15 minutes.
- General Questionnaire: Questionnaire developed for this current study by Oppenheimer et al. that consists of twelve items that assess religious aspects and the influence of religiousness on quality of life of women with fertility problems. The questionnaire administration time was approximately 5 minutes. Patients were asked to what religion or belief system they adhered, how often they participated in religious celebrations, and if this helped in coping with infertility, as well as other questions.

Data were analyzed using SPSS 18.0 for Windows®. Descriptive analysis was performed, with presentation of frequencies and percentages in each group, for the studied variables. Groups were compared using a Chi-square test. Statistical significance was set at 5%.

Results

In total, 104 volunteer women responded to the questionnaires. The first 26 questions corresponded to the FertiQoL questionnaire and the last 12 questions corresponded to the general questionnaire. Results are presented below, according to the order of the questions.

Individual perception of quality-of-life questions demonstrated that 89% of patients undergoing infertility treatment view their health as good or very good, and 61% are satisfied with their quality of life. On the other hand, many patients (67%) reported decreased concentration due to thoughts about infertility. In terms of dealing with the problems of infertility, 43% of patients reported they were able to advance their life plans despite fertility problems, but 26% find it moderately difficult and 31% reported difficulty. Also, 37% of patients felt very or completely exhausted. However, 53% of respondents felt they were partially able to deal with their problems of infertility.

Several women (45%) were very satisfied with the support they have received from friends, but 35% admitted they were more or less satisfied and 20% said they were little or not at all satisfied with the support they received from friends. Most (69%) also reported they are satisfied with their sex life, despite infertility and, although there is difficulty in achieving pregnant, 63% of patients report they are affectionate with their partners (and vice versa), and only 7 % report they are rarely or never affectionate.

When asked about their feelings, 61% of women reported they never or rarely are jealous or rancorous due to infertility, but most patients report to be anguished: 46% all the time or often, and 35% sometimes. Most (79%) fluctuate between hope and despair rising from infertility, and over half (51%) feel isolated.

Half of respondents described their infertility issues interfered with their daily obligations. Moreover, 58% of patients declared discomfort in social situations. However, only 20% felt their family never or rarely understood the problems they were facing, 34% responded their family sometimes understands them, and 46% feel that family members are often or always able to understand the infertility problems they face. Moreover, 53% of women interviewed stated their dedication to their partner was strengthened due to their infertility.

Patients also responded feelings of sadness related to infertility: 45% reported the often or always felt sad and depressed, 32% rarely or never and 23%, sometimes. Also, most patients reported feelings of inferiority to child-bearing persons (71%). Finally, 54% of patients described fatigue.

Although 53% of responded had declared their relationship strengthened due to infertility, 68% indicated a negative impact of infertility on their conjugal life, and 53% admitted difficulty in communicating with their partner about infertility. Most (76%), however, are satisfied with their relationship. Aside from difficulty in achieving

pregnancy, 50% of patients often or always and 21% sometimes feel social pressure to have children and many (69%) patients feel irritation due to infertility; 51% do not feel physical pain.

The general questionnaire indicated that 66% were in their first treatment, 57% seek or had sought alternative treatments, and 84% changed to a healthier lifestyle. It also provided information about the patients' religion/sect or belief. Most patients declared they followed some religion (figure 1), and most (68%) are engaged in its activities. More than half attend a session, at a temple or equivalent, at least once a week.

In total, 62% of women did not change their religious habits due to infertility. It was found that 93% of patients resort to prayers or religious texts, and religiousness is important to the well-being of 95% of respondents. Most (71%) patients read religious texts or pray daily and 88% believe prayer helps them face their difficulty in achieving motherhood. Patients related that prayers bring them hope (47%), calm (18%), comfort (12%), tranquility (10%), or inner peace (10%), and 3% feel praying is important for personal growth.

The results of the analysis of variables that showed a significant difference in the comparison using the chi-square test are presented below. Patients were more satisfied with their quality of life when they had altered their lifestyle ($p<0.05$) (figure 2).

Women more or less satisfied with the support they have been receiving from friends regarding infertility were those that considered religiousness less important than either women that declared to be satisfied or unsatisfied with support received from friends. These patients also reported more frequently to resort to prayer or religious reading when compared to women that were mostly or completely unsatisfied with support received from friends.

Patients that reported frequently or always feeling jealousy or rancor due to infertility more frequently altered their habit to attend sessions at a temple or equivalent. Patients that never or rarely fluctuated between hope and despair (13.6%) less frequently altered their habit to attend a session at a temple or equivalent. On the other hand, patients that felt isolated more often altered their habit to attend a session at a temple or equivalent, as did patients that related discomfort in social situations.

Patients that reported to feel understood by their families regarding infertility only at times more frequently sought prayer or religious reading, when compared to

patients the never or rarely felt understood. Also, patients that reported feelings of sadness or depression often or always more frequently altered their habit of attending sessions at a religious temple or equivalent when compared to women who rarely felt sad (figure 3).

A lower percentage of women declared that infertility negatively impacted their relationships when they participated in any religion, than in those that did not. Patients that reported social pressure to bear children often or frequently were more frequent in their attendance at religious temples or equivalents, and more frequently prayed or read religious texts.

Patients often or always irritated at infertility issues were also more prone to alter their religious habits in terms of frequency of attendance, when compared to women seldom or never irritated. Moreover, patients in a first treatment cycle were less prone to alter that habit. Finally, patients that changed to a healthier lifestyle were less prone to attend sessions at a religious temple or equivalent than patients who did not.

Discussion

Achieving motherhood and fatherhood is a central purpose for couples of many different cultures **(25)** and receiving a diagnosis of infertility goes well beyond physiologic and laboratory issues, leading to a psychological process characterized by changes in habits and religious standards for couples. Women that deal with infertility undergo not only a physical, but also an emotional process, before and during infertility treatment **(15,26,27)**. It is understood, then, that infertility treatment also encompasses mental health in many couples; as demonstrated, difficulty or impossibility to achieve pregnancy may lead to feelings of anguish or inferiority to child-bearing people.

This study allowed us to observe the effects of infertility on women in a Brazilian cohort, demonstrating infertility leads to medical situations, as well as social, familial, and religious issues. Moreover, we have demonstrated the manner through which patients cope – both emotionally and socially – with infertility, and their changes in habits following diagnosis of infertility. It is important to emphasize that it was appropriate for the analysis of this study to consider religiosity and spirituality as a single aspect, understanding that spirituality is a personal path in search of meaning to questions about life, and religiosity is related to the individual's belief and religious practice **(18)**. Furthermore, it is also important to clarify that scientific evidence shows

the importance of prayer and spirituality in the quality of physical and mental health of patients, as well as in the way they respond to stressful situations **(28)**.

Thoughts of infertility were associated to disturbance in concentration, and many women found it difficult to move on with their life plans; this, in turn, as was demonstrated by Tamannaifar (2011), could lead to feelings of dissatisfaction in life **(29)**. Conversely, results showed that women were resilient to negative feelings and leading with difficulty, because, although many felt exhausted due to infertility, most demonstrated confidence in dealing with the problem.

Many studies have demonstrated reduced self-confidence, increased anguish, depression, stress, and sexual dissatisfaction stemming from infertility, directly affecting quality of life **(6,7,30)**. In our study, 81% of women admitted to feelings of anguish, and most related they alternated between hope and despair, demonstrating that infertility is associated to emotional distress. A study by Rooney (2018) demonstrates that negative feelings arising from infertility such as shame, guilt and low self-esteem can lead to different degrees of depression and anxiety **(31)**. Also, many women confirmed social crises, stating they feel discomfort in participating in social events, corroborating with authors who state that the majority of infertile women do not share their journey and adversities with friends and family, thus increasing their psychological vulnerability **(31)**. Karaca and Unsal (2012) discuss this, when they state that, in some societies, infertility leads to incapability of living up to social expectations **(32)**.

Moreover, at many times, couples in treatment for infertility seek support from religion, leading to improved resilience and quality of life. Importantly, results in our study demonstrated women that were satisfied with their quality of life more frequently altered their habit of attendance at religious temples or equivalents. There is a need to clarify here that, although there is no consensus on the definition of quality of life, according to the WHO, quality of life is an individual's perception of their position in life, in the context of culture and value systems in which that individual lives in relation to his or her goals, standards, concerns, and expectations **(33)**.

In regards to religion, 68.34% of respondents declared to participate in some religious activity, of which 50% were Catholic. Klitzman (2018) stated that a search for religious belief leads to improved outcomes in infertile patients, and that this is expected in situations of internal conflicts in patients **(34)**. In a study in the USA, 51% of respondents were protestant, and 26% Catholic **(17)**. This occurs because of

sociodemographic differences between the USA and Brazil – in the latter, Roman Catholicism is the predominant religion, which explain results in this study **(4)**. In regard to aspects related to religious practice, 93.23% of participants stated they regularly prayed, and two-thirds that they read daily passages from religious texts. Braga et al. (2019) stated that most patients in their study referred regular prayer and religious reading, as in our study. The authors infer that decreasing frequency of prayers negatively associated to a positive outcome, while maintaining prayers improved response to ovarian stimulation **(21)**.

It is important to highlight that the possible support that infertile women seek in religiosity/spirituality is a very personal aspect, difficult to measure, but it is noted that the search is a coping mechanism and a different view of reality. Through the interviews carried out in this study, it is suggested that religion and/or spirituality can convey a sense of comfort and, mainly, of hope, making it possible to believe in the main achievement of life, even if there is difficulty in achieving it.

Religiousness was referred by 95.19% of participants as bearing a positive impact in patients' well-being, and 9 in 10 respondents identified religious belief as a support mechanism for coping with infertility. These results demonstrate a positive role for religiousness in improving patient well-being during treatment, which agrees to findings from Casu et al. (2018), who stated that spirituality and religiousness may provide a positive resource in dealing with infertility, as a means for improved quality of life in these couples **(35)**. A study with 264 women undergoing infertility treatment identified as the main negative feeling attributed to failure to achieve pregnancy was depression, and that hope was the predominant feeling when they sought medical care **(36)**, as was found in this study.

When we sought to verify patient satisfaction with support from family and friends and with daily prayers, we observed that patients were most satisfied with support from friends in women with daily religious habits. Therefore, frequent religious habits were better prepared to understand their situation and face the sentimental challenges, which is in accordance to Grinstein-Cohen et al. (2017), who identified that patients declared that social difficulty and experience were more painful than treatment itself, and that religiousness improved negative feelings **(37)**. Collins et al. (2018) further demonstrated the importance of religiousness in facing infertility by showing that three in four patients seek religious or spiritual support, while little over half seek medical care **(17)**.

In regards to feelings of sadness and depression stemming from infertility, when related to attendance in religious temples or equivalents, results from our study demonstrated a gradual increase in search for religion in women with negative feelings towards infertility, demonstrating these women seek emotional support in spirituality of religiousness. This is in accordance with Romeiro et al. (2017), who described that the adversity these patients underwent produced spiritual needs in these women as a coping mechanism, incorporating religious teachings as tools to overcome these challenges **(38)**. Likewise, when irritability was correlated to search for religion, increased attendance was found in women with higher stress levels, similar to the Portuguese study. Tiu et al. (2018) further demonstrated the need for psychological support for patients with increased irritability or stress due to ovulation problems attributed to mood swings **(39)**. The study also suggests that spiritual or religious measures should be employed in order to reduce stress, thus improving results.

Social pressure to bear a child has been related to religious reading habits and to frequency or attendance in religious temples or equivalents, and in both cases, increased social pressures were associated to increased religious habits. Öztürk et al. (2021) agree with results from this study, demonstrating that social pressure in infertile women is greater than that faced by primiparous fertile women, and that this leads to emotional distress with a need for psychological support, either by specialized psychologists, or by religious practice **(40)**. As a socioeconomic counterpoint to the previous findings, a study from Gambia demonstrated similar results regarding psychological pressure and the search for spiritual support, demonstrating that African populations are prone to seek, frequently, solace in biblical texts or in religious temples **(41)**. Hanselin et al. (2017) stated that infertile patients tend to seek emotional support in religion, but also acknowledge that some religious views may increase psychological pressure in patients **(42)**. Therefore, spirituality and religiousness may play important positive roles in dealing with social pressure faced by patients; however, they suffer the influence of conservative interpretations, which may lead to increased emotional angst.

Limitations

The present study, as it touches on personal issues of respondents, has some limitations. First, number of participants was lower than initially planned. We also noted difficulty of the interviewees when the approach had intimate repercussions, such as

marital relationship and family life. In addition, there was no characterization of the studied sample regarding the underlying disease, duration of infertility, male or female factor of infertility, age, and other demographic data. Finally, the relationship between attitudes of coping with infertility was not sufficiently clarified, but the positive result of spirituality could be noted.

It is important to highlight the difficulties encountered in the study as a recommendation for future investigations on the same topic.

Conclusion

This study sought to elucidate how patients cope with infertility. It is noteworthy that religiousness leads to improved adaptive capacity, due to the spiritual quest to decrease suffering brought upon by the absence of children, and by improving quality of life. Sadness, depression, irritability, lower quality of life, and social discomfort were greater in patients with no religious belief, as was a decreased perception of support from family and friends.

While the exact relations may not have been adequately demonstrated, results from this study strongly suggest that spirituality plays an important role in adjusting psychological aspects of infertile patients.

Declarations

Ethics approval and consent to participate

Institutional review board approval was received from the Itajubá School of Medicine (project number 3.846.249). Resolution 196/96 guidelines from the Brazilian National Health Council were followed.

Consent for publication

Not applicable

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Not applicable

Authors' contributions

DO – conception of the study, data collection, results interpretation, drafting of the manuscript. Final approval for submission.
CC – conception of the study, results interpretation. Final approval for submission.
GF – conception of the study, results interpretation. Final approval for submission.
CF – conception of the study, data collection, results interpretation. Final approval for submission.
FR – conception of the study, results interpretation, correction of the manuscript. Final approval for submission.
RN – conception of the study, results interpretation, correction of the manuscript. Final approval for submission.

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Figures

Figure 1. Question 27: what is your religion/belief, if any?

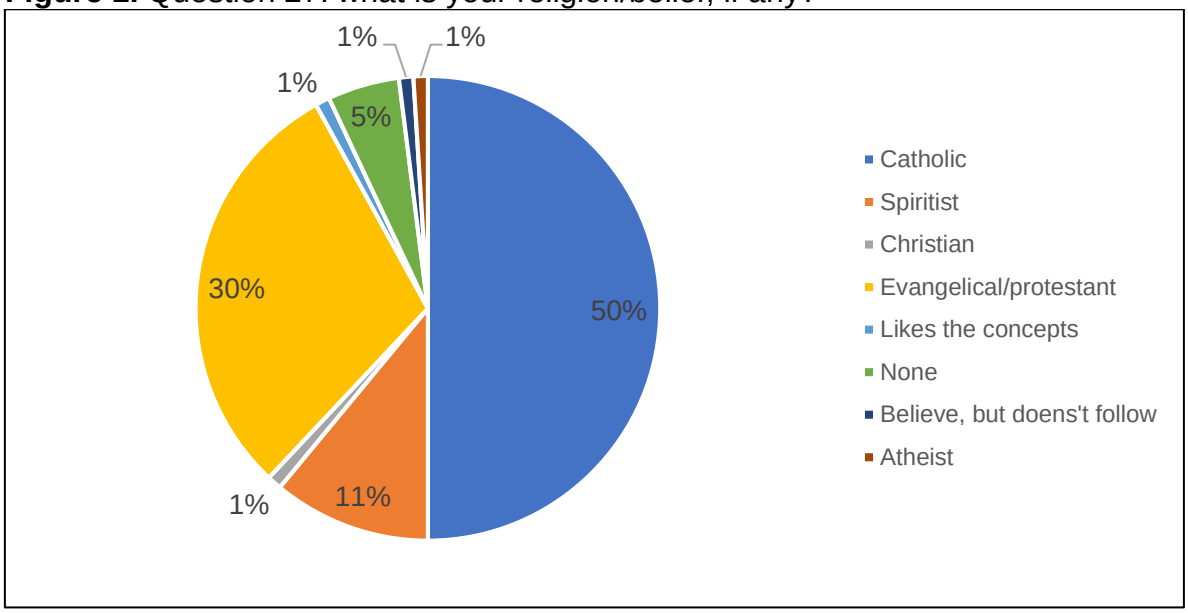


Figure 2. Comparison of change in religious habit in women according to their satisfaction with quality of life.

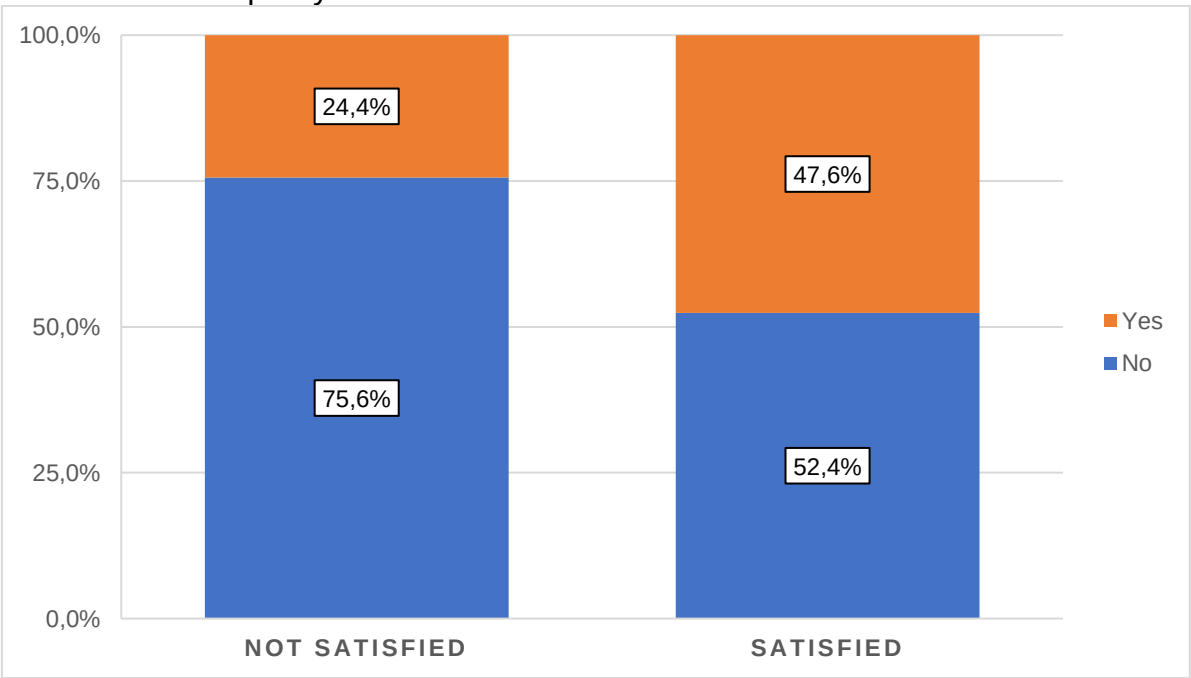


Figure 3. Comparison of change in habit of attending sessions in a temple or equivalent in women according to their frequency of feeling sad or depressed.

