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Perspectives on access to in vitro fertilization in Portugal

Perspectivas sobre o acesso aos tratamentos de fertilidade em Portugal

ABSTRACT

OBJECTIVE: To analyze users' reasons for choosing *in vitro* fertilization treatment in public or private services and to identify their suggestions for improving fertility treatment.

METHODS: A qualitative study using an interpretative approach was conducted. Fifteen semi-structured interviews were conducted with patients undergoing *in vitro* fertilization treatment (nine women, one man and five couples) at home or at their workplace in the districts of Viana do Castelo, Braga, Porto and Lisbon, Portugal, between July 2005 and February 2006.

RESULTS: Users evaluated access to *in vitro* fertilization treatment in public and private services based mainly on their individual experiences and called for more access to less costly, faster and friendlier care with suitable facilities, appropriate time management and caring medical providers. These perceptions were also associated with views on the need for fighting stigmatization of infertility, protecting children's rights and guaranteeing sustainability of health care system. Interviewees sought to balance reduced waiting time and more attentive care with costs involved. The choice of services depended on the users' purchase power and place of residence and availability of attentive care.

CONCLUSIONS: Current national policies on *in vitro* fertilization treatment meet user's demands of promoting access to, and quality, availability and affordability of *in vitro* fertilization treatment. However, their focus on legal regulation and technical-scientific aspects contrasts with the users' emphasis on reimbursement, insurance coverage and focus on emotional aspects of the treatment. The study showed these policies should ensure insurance coverage, participation of user representatives in the National Council for Assisted Reproductive Technology, promotion of infertility research and certification of fertility laboratories.

DESCRIPTORS: In Vitro Fertilization. Health Services Accessibility. Infertility, psychology. Sexual and Reproductive Rights. Qualitative Research.

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RESUMO

OBJETIVO: Analisar as motivações para escolha de tratamentos de fertilização *in vitro* em serviços públicos e privados, bem como identificar propostas que melhorem a qualidade desses.

MÉTODOS: Estudo qualitativo e interpretativo, baseado em 15 entrevistas semiestruturadas com pessoas que tentaram conceber por meio de técnicas de procriação medicamente assistida em Portugal (nove mulheres, um homem e cinco casais). As entrevistas foram realizadas entre julho de 2005 e fevereiro de 2006 nos distritos de Viana do Castelo, Braga, Porto e Lisboa, em casa ou no local de trabalho dos entrevistados.

RESULTADOS: Os usuários avaliaram o acesso aos tratamentos de fertilidade no serviço público ou privado sobretudo com base nas suas experiências individuais, reclamando acesso mais barato, rápido e amigável, em espaços adequados, com gestão apropriada dos tempos de espera e serviços médicos atenciosos. Tais percepções foram associadas a visões sobre a necessidade de combater a estigmatização da infertilidade e defender os direitos da criança e a sustentabilidade do sistema de saúde. Os entrevistados procuraram equilibrar a redução do tempo de espera e cuidados mais atenciosos com os custos envolvidos. A escolha dos serviços dependeu da renda e do local de residência dos usuários, além da existência de cuidados atenciosos.

CONCLUSÕES: As atuais políticas nacionais vão ao encontro das expetativas dos utilizadores ao promover o acesso aos tratamentos de fertilidade e a sua qualidade, mas distanciam-se delas ao enfatizarem a regulação jurídico-legal e a dimensão técnico-científica da qualidade na procriação medicamente assistida em detrimento do acionamento de seguros de saúde e da valorização de aspetos emocionais. As políticas a implementar passam pela cobertura obrigatória dos tratamentos pelos seguros de saúde, pela inclusão de um representante dos usuários no Conselho Nacional de Procriação Medicamente Assistida, pela promoção da investigação sobre infertilidade em Portugal e pela certificação dos laboratórios que realizam testes de fertilidade.

DESCRITORES: Fertilização In Vitro. Acesso aos Serviços de Saúde. Infertilidade, psicologia. Direitos Sexuais e Reprodutivos. Pesquisa Qualitativa.

INTRODUCTION

The World Health Organization (WHO) established as a global goal for the new millennium to improve women's access to infertility treatment, and availability and affordability of infertility services,[6] which can contribute to the delivery of optimal infertility care.[9] Portugal has taken this directive to task and medically assisted reproduction is a major issue in the recent structural reforms of the Portuguese health sector.[a] Since 2006 Portugal has implemented several initiatives to scale up access to infertility treatments and improve affordability of these services including: sanctioning of the first law on assisted reproductive technologies on July 2006;[b] implementation of standard care quality and costs and quality monitoring;[c] partnerships with private providers of infertility treatment, which began operating in the mid-2009; public coverage of 69% of the total cost of infertility medication since the mid-2009;[d] creation of new public reproductive care units in 2009

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[a] Portugal. Despacho n. 14788, de 6 de maio de 2008. Cria o projecto de incentivos à Procriação Medicamente Assistida. *Diario Republica Portuguesa*. 28 maio 2008:23832-3.

[b] Portugal. Lei n. 32, de 26 de julho de 2006. Regula a utilização de técnicas de Procriação Medicamente Assistida. *Diario Republica Portuguesa*. 26 jul 2006:5245-50.

[c] Portugal. Portaria n. 154, de 9 de fevereiro 2009. Aprova a tabela de preços para tratamentos de procriação medicamente assistida. *Diario Republica Portuguesa*. 9 fev 2009:867.

[d] Portugal. Despacho n. 10910, de 29 de abril de 2009. Comparticipação de medicamentos para o tratamento da infertilidade, em especial os da procriação medicamente assistida. *Diario Republica Portuguesa*. 29 abr 2009:17165-6.

in smaller localities where assisted reproductive technologies were not available. Nevertheless, management of infertility treatment in Portugal can be a case study that reveals inequalities in access to reproductive health. There is no insurance coverage of infertility treatment, reproductive care units are geographically concentrated, infertility services proliferate in the private sector, and restriction of potential users to heterosexual couples.[12]

Access and quality of care issues should take into account local cultural, social, economic and political dimensions of reproductive medicine.[7,8,14] The Portuguese National Health Service provides free access to first-line infertility treatment for women under the age of 42, and second-line treatment for women under the age of 40. Ovulation induction treatment is covered as well as up to three intrauterine insemination cycles and three in vitro fertilization (IVF) or intracytoplasmic injection cycles. In Portugal, the main arguments used by public sector providers to justify restriction on the number of treatments and eligibility criteria are inadequate human health resources, limited physical space, inadequate infrastructure and long waiting time.[12] However, policies on the total number of infertility treatments and maximum age for a couple to undergo infertility treatment vary according to individual centers and they are less restrictive in the private sector. Some providers work both in private and public sectors, and there is no accurate data about comparative advantages in terms of effectiveness, equality of access and quality of infertility and reproductive care between public and private services in Portugal.[11]

Earlier studies have shown that priority-setting mechanisms and practice guidelines can be improved with small-scale, qualitative research data that take into account the patients' needs and experience.[2,3,9] This study aimed to evaluate users' reasons for choosing public or private IVF treatment and to identify their suggestions for improving infertility treatment.

METHODS

A qualitative study using an interpretative approach was conducted. Participants were recruited via e-mail with the use of a snow-ball strategy; the first author sent an e-mail message to colleagues at work and friends asking them to pass it on to other people. Purposive sampling was used, i.e., new data were added to the analysis when they were of theoretical interest, and the sample size was determined by data saturation.[5] This sampling approach aimed to recruit a varied range of participants taking into account the category (public and/or private) of the clinic where they sought infertility treatment.

Fifteen semi-structured interviews were completed, five by couples and the remaining by individuals (nine women and one man), depending on their availability to participate in the study. Interviews were conducted at the participant's home or workplace in the districts of Viana do Castelo, Braga, Porto and Lisbon between June 2005 and February 2006. Each interview took on average 90 minutes. Transcripts of the interviews were checked for accuracy.

Information on sociodemographic variables (age, education, occupation, nationality, parental status and family income) and infertility treatment characteristics (cause of infertility, number and outcome of treatment cycles and place of treatment) was collected. Answers to two open questions were selected: reasons for choosing a particular reproductive care center and suggestions for improving infertility treatment. Qualitative data were then systematically coded and summarized around two core themes: users' reasons for choosing public or private services and their assessment of political, social and practice priorities in medically assisted human reproduction in Portugal.

The study was approved by the Foundation for Science and Technology (Portuguese Ministry of Science and Education – 10396/2002). The Ethics Code of the International Sociological Association was followed. Verbal consent to conduct and record the interviews was obtained from the participants after they were explained they could refuse to participate or answer any question and their anonymity was guaranteed.

RESULTS

A total of 20 individuals participated in the study. They were all Portuguese and, as dictated by the Portuguese law as a requirement for access to infertility treatment, they were all heterosexual and married. Sociodemographic and obstetric characteristics of the interviewees are shown in the Table. The most common household arrangement was legally married couple with no children (n=8). Four couples had IVF-conceived children, two had "naturally" conceived children after undergoing infertility treatment and one couple had an adopted child. Of a total of 57 treatment cycles, 12 resulted in a pregnancy with an outcome of a healthy newborn (n=6) and miscarriage (n=6). Female factor infertility was seen in eight couples, male factor in two, male and female infertility in one and no diagnosis was available in four. Four participants received infertility treatment in a public setting, eight in a private setting, and the remaining three participants received treatment in both public and private settings.

The choice between public and private services depended on economic, social, and organizational factors including: financial costs involved; the couple's expected time for treatment to begin; type of medical care expected; and place of residence. In general, the interviewees considered if they could afford the treatment, and then they sought for shorter waiting time for

Table. Sociodemographic and obstetric characteristics of interviewees. Portugal, 2005–2006.

Characteristics	Total
Age (years)	
30–34	8
35–39	9
40–45	3
Gender	
Female	14
Male	6
Education	
9 years	4
12 years	2
College education	14
Occupation	
Technician and associated professions	6
Manager	5
Service and sales representative	6
Armed forces staff	1
Intellectual and scientific professions	2
Monthly family income[a]	
<2000 €	2
2000–3000 €	7
>3000 €	6
Parental status	
No children	8
Children	7
Source of infertility	
Female factor	8
Male factor	2
Female and male factor	1
Unknown/unexplained	4
Category of service	
Public	4
Private	8
Public and private	3
Total number of treatment cycles	57

[a] The monthly minimum wage in 2005 and 2006 was € 374.70 and € 385.90, respectively.

treatment and friendly care. For instance, a female interviewee who had access to private infertility treatment said they were compelled to seek public care as they no longer could afford private treatment. As a result of their decision, the couple had to face two consequences: they waited much longer than expected to start treatment; and they both had to repeat all fertility tests, which was especially difficult for the woman who reported them as being "painful" and "invasive." One couple tried to pay the costs and shorten the waiting time by resorting to their personal and family contacts in the public sector while receiving treatment in a private center.

When interviewees were asked to compare the advantages between public and private care, they often mentioned low cost of public care and faster, more caring, and better organized private care which also offered them more privacy and freedom. A female interviewee shared her experience and told she felt they "lacked in consideration" in the public sector:

"*I don't feel they give the same importance in the hospital* [as in a private clinic]; *it* [the appointment] *just lasts 5 or 10 minutes, they see you, there is nothing new, please come back next month*".

Another female interviewee mentioned that a private treatment provided her the opportunity of receiving care from the same doctor and saw it as a "benefit" that one cannot afford in the public sector.

The interviewees also highlighted the space arrangement of infertility centers because it reflected service friendliness. A female interviewee described a public infertility unit as "awful" because medical consultations were conducted in a basement where *"the light is dim, there are no windows… and people have to go downstairs to find a rather dark place."* Another female interviewee criticized the management of medical departments in a public hospital as the reproductive medicine, obstetrics/gynecology and family planning units were all in the same area saying:

"We don't want to be seen separately, but at least they shouldn't see us near [an environment] *what hurts us*".

Contrasting with these narratives, one of the couples interviewed described some of the rooms in a public infertility center as "friendly" and emphasized the "positive effect" of placing "many pictures of babies" on the walls while private rooms were described as "impersonal" and "cold" that became "empty" and "too large taking given the things they have inside."

One male interviewee explained he had chosen a particular private infertility center as the limitation of the number of cryopreserved embryos matched the couple's values and expectations. He claimed that he chose "the clinic of someone [medical doctor] (…) I thought was more in line with my [moral and ethical] values [to avoid the production of surplus embryos]." But choice could be restricted in the public sector where patients have access to infertility treatment in a hospital near their place of residence. Furthermore, a couple who was considering switching doctors during an infertility treatment at a public clinic changed their minds after a conversation with the hospital's psychologist who reminded them that changing providers would not mean that the former doctor would not be involved in their medical procedures, because rotation of public providers is common in Portuguese hospitals:

"*We tried to switch doctors. (…) We talked about it with the* [hospital's] *psychologist.*" (male interviewee)

"*And the psychologist reminded us that in the future they'll work as a team in the hospital (and it did really happen). (…) So we decided not to change doctors.*" (female interviewee)

The interviewees faced the following challenges of access to care services in medically assisted human reproduction: difficult access to information and knowledge; scientific and technological research limitations; and limited innovations in the industry. A female interviewee criticized the lack of investment on the development of new drugs for ovulation induction:

"*The medication I'm taking is the same one I took four years ago. So it's the same thing, it has not have much development*".

A male interviewee also said that the development of "*more medical studies*" should be a priority in order to make infertility treatment "faster" and "easier." Considering the social, emotional, and physical burden of infertility treatment, almost all interviewees believed psychological support should be compulsory in IVF clinics.

The interviewees mentioned what should be the Portuguese government involvement in medically assisted reproduction in economic and financial aspects: further national policies regarding reimbursement of medication, consultations, and fertility tests; decentralization and expanding the supply of reproductive medicine units; and promoting the dissemination of information about infertility. These views reinforce the assumption that ethical and legal aspects were not regarded as relevant political issues.

Almost all participants (18 out of 20) supported the idea that there should be cooperation between medically assisted reproduction services available in the public and private sectors in Portugal. They agreed on the privatization of reproductive care but also called for more public investment. But this supporting view could be weakened by the fact that the sample interviewed had a relatively higher income, as well as by the perception of financial problems faced by Portugal, in general, and constant budget deficit of the Portuguese Ministry of Health, in particular.

Besides the Portuguese government involvement in financial and economic aspects, the participants underlined the importance of promoting social and cultural changes to improve the well-being of women and men experiencing infertility. In the following narrative a male interviewee mentioned the need to deconstruct childlessness as an "abnormality" and fight against its social stigmatization:

"*I think the environment is important, isn't it? People should respect our space and at the same time they shouldn't treat us like abnormal people. But it is very hard because it is part of general education. And it is even harder because fortunately there aren't so many cases* [of infertile couples] *(…) and no one really talks about them.*" (male interviewee)

The ethical dimensions of the decision-making process were perceived as citizens' responsibilities, in which children's rights and interests were highlighted. These principles, alongside limited public financial resources, were the main criteria used by the interviewees to support the legal and political requirement of heterosexual couples to have access to infertility treatment in Portugal. No participant suggested the regulation of assisted reproductive technologies as a mechanism that could improve the situation of couples experiencing infertility.

DISCUSSION

Users' perspectives on access to IVF treatment in Portugal mainly reflect their individual experiences. They stressed the need for more access to health care resources, and that services should be less costly, faster and friendlier. All interviewees mentioned the comparative advantages in effectiveness, equality of access and quality of care in public and private sectors. But we concluded that the most satisfied users are those who described their infertility treatment as patient-friendly, i.e., treatments carried out in suitable settings with appropriate time management and caring medical providers. But these accounts were also associated with the interviewees' perceptions of broader social, cultural and economic aspects such as stigmatization of infertility, children's rights and sustainability of the Portuguese health care system.

These views emphasize the importance of the so-called "limited resources argument"[6] on the perceptions of IVF couples that is associated with basic principles of the Portuguese health system, namely: equity of access, universal coverage and provision of high-quality health care.[13]

The accounts of patients experiencing infertility of their access to infertility treatment in Portugal need to be further quantitatively explored and other voices should be heard including those of people with different ages and social and educational backgrounds, which were not studied here. The strengths of this study lie on its original insights to the debate of accessibility to infertility treatment in local policies. Patients experiencing infertility and national policies concerning medically assisted human reproduction pursue common objectives: to improve their access to care and quality, availability and affordability of these services. In order to achieve them, and in accordance with users' accounts, the Portuguese government should establish partnerships with the private sector, increase public coverage of infertility medication, expand and decentralize the supply of public reproductive services and ensure psychological support for these patients. But there are also contrasts between users' accounts and national policies. The regulation of assisted reproductive technology is a political priority while users identify insurance coverage as their priority. National policies emphasize technical and academic requirements for standard quality care while users highlight its emotional dimensions such as friendly space arrangement of infertility centers and more caring medical services.

Bearing in mind the generally high cost of infertility treatment, lack of insurance coverage, availability of reproductive care units mainly in major urban centers and the strong role of the private sector, recent Portuguese policies on accessibility and reimbursement still leave many IVF couples without treatment options. The findings of our study point out several recommendations for improving the priority-setting mechanisms and practice guidelines at national and international levels:

- To promote universal friendly, affordable, accessible, and simplified reproductive technology methods. This may be achieved through a rearrangement of the global reproductive health care budget[6] and health partnerships.[10] Local management and accountability may be important in improving cost-sharing and implementing new equitable health insurance schemes, such as community-based health insurance. Private health insurance should be regulated[13] in order to include the reimbursement of infertility treatment.
- To meaningfully discuss assisted reproductive technologies focusing on users' experiences.[2,3] Multiple strategies to promote public involvement in the development of health policies on assisted reproductive technologies need to be used such as arts-based approaches and traditional consultation like consensus panels.[1] Users' empowerment in decision-making processes may be reinforced through more inclusive priority-setting processes including participation in councils on assisted reproductive technologies with at least one member representing IVF couples; and the government should promote increased awareness of infertility through local research projects aiming to address the medical, legal, ethical, social, cultural, psychological and political dimensions of infertility treatment.
- The recent certification of reproductive care centers must be extended to laboratories that can perform fertility tests. It can prevent IVF couples seeking treatment to have repeated fertility tests at different clinics. The number of infertility treatments a patient may undergo in the public sector should be increased and there should be established a maximum age for both women and men for infertility treatment as well as a clear definition of criteria to be used to restrict access to infertility treatment.

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